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ABSTRACT

The monograph presents guidelines for early intervention services for handicapped infants and their families. Guidelines are the result of a 1980 conference on health issues in early identification programs. Three state of the art papers are included: "Infancy, What We Know and What We Need to Know as a Basis for Intervention" by A. Korner; "Child Change in an Early Intervention Program for the Developmentally Disabled" by J. Howard and L. Beckwith; and "Infant Intervention: Parental Considerations" by K. Barnard and J. Kelly. A paper on contemporary theory covers such aspects of the subject as a clinical continuum of disability recognition, immediate postnatal care, and followup and screening. Recommendations focus on protecting physical health; promoting psychosocial development; and facilitating motor, cognitive, and communication development and self care skills. The state agency's role in planning and monitoring services is examined. Appendixes contain papers on Utah's infant development program and on Hawaii's enrichment project for handicapped infants, staffing considerations, references, and a list of participants. (CL)

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Guidelines for Early Intervention Programs

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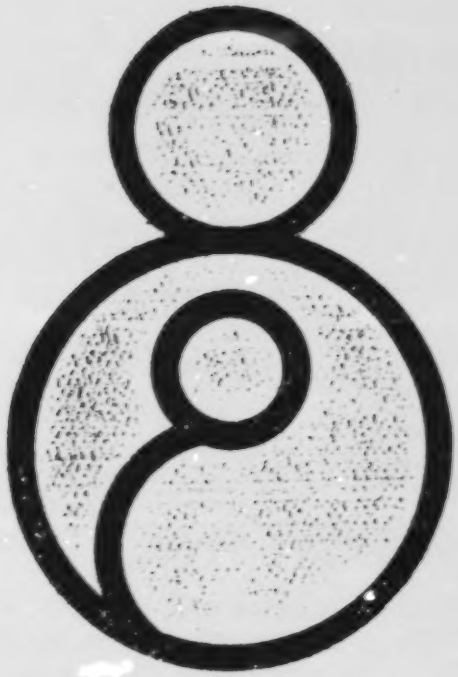
Based on a Conference

HEALTH ISSUES IN EARLY INTERVENTION PROGRAMS

May 1980

Washington, D. C.



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GUIDELINES FOR EARLY INTERVENTION PROGRAMS

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HEALTH ISSUES IN EARLY INTERVENTION PROGRAMS

May 1980

Washington, D. C.

Sponsored By

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I. PREFACE

For a number of years the State Maternal and Child Health and Crippled Children's Services programs have provided early intervention services for infants with discernible handicaps and their families. More recently, other federally supported programs such as Developmental Disabilities, Early Periodic Screening Diagnosis and Treatment, Head Start, P.L. 94-142, Education for the Handicapped, Title XX Social Services, and the National Institute for Mental Health have emphasized the need for early intervention on behalf of these vulnerable infants. These guidelines have been developed primarily for the use of those who staff these and other programs which provide services to infants and young children.

These early intervention guidelines should be considered as an initial attempt to produce a useful document for staff at the service delivery level and should not be viewed as being the final authoritative word on this important and controversial subject. It is recognized that there are many points of view concerning early intervention, and that more research is needed before disagreements as to approaches can be resolved. Therefore, this version of the guidelines is being issued as a working draft to give all interested parties an opportunity to comment and to make suggestions for its improvement. It will be desirable to make use of the experience in using this document to revise and improve upon the guidance material which it contains. Any comments, suggestions or initial analysis of the material will not only be welcome but are encouraged by December 15, 1981.

These guidelines are the result of the May 1980 Conference on Health Issues in Early Intervention Programs which was sponsored by the Office for Maternal and Child Health with the College of Nursing of the University of Utah and the School of Public Health of the University of Hawaii.

This conference attracted a number of experienced professional individuals whose expertise is reflected in these guidelines. A listing of these contributors appears in Appendix E.

The Office for Maternal and Child Health would like to give special credit to Athleen Coyner, R.N., M.S., and Setsu Furuno, Ph.D., who were Project Directors for the Conference and were largely responsible for its success and for its contribution to the resulting guidelines.

We are particularly grateful to Kathryn Barnard, R.N., Ph.D., Judy Howard, M.D., Alfred Healy, M.D., and Annelise Korner, Ph.D., for their direct contribution to the development of these guidelines.

Special recognition and appreciation must go to Merle G. McPherson, M.D., M.P.H., and Camille L. Cook, R.N., M.S. They not only conceived the idea for these guidelines but are largely responsible for focusing professional expertise on this important subject so that these guidelines could be developed.

Additional copies of these guidelines may be obtained from the Office for Maternal and Child Health.

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II. INTRODUCTION

In recent years increased emphasis has been placed on the follow-up of handicapped and high-risk infants and this has been accompanied by a rapid increase in the number of programs which are known as infant development, infant stimulation, high-risk, sensory-motor and early intervention programs. These guidelines are intended to provide current information about early intervention programs for infants from 0 to 3 years of age with discernible handicaps and their families, and to assist policy makers and program directors in the planning and implementation of such programs.

They have been developed primarily for the Directors of staffs of the State Maternal and Child Health (MCH) and Crippled Children's Services (CCS) Programs. However, it is hoped that they will be made available to and used by other agencies and individuals who provide early intervention services for infants from 0 to 3 years of age with discernible handicaps. Unless otherwise indicated, the term infant will be used throughout the guidelines to denote this age group.

With the publication of these guidelines which focus only on this group, it is not intended to ignore the larger number of infants and children at risk for underachievement in life skills solely because of social or environmental reasons. However, it is recognized that there are numerous publications which concern early educational intervention programs for these children as well as research on their effects.

These guidelines support the concept of early intervention programs for infants with biological impairments, and their families. We believe programs should be organized within the health delivery system and be family centered. While current research on long-term outcomes is needed, there is considerable evidence of change particularly in social competency skills. The medical profession can do little to change the neurological status of an individual infant, but pediatricians and other health and education professionals can provide early assistance to promote optimal health and developmental experiences for infants and families.

The primary purpose of early intervention programs is to strengthen the family and to integrate the infant/child with a discernible handicap into the family unit in a positive way within the context of the needs and well-being of all the family members.

Participants in the Conference on Health Issues in Early Intervention Programs expressed concern for infants in intensive care units who are being placed in infant simulation programs in increasing numbers. Recent research has demonstrated the capacity of the newborn to process sensory input, and indicates that infants differ in this capacity so that for some the environment may provide a stimulus overload because of sensory hypersensitivity. On the other hand, there is a paucity of research to determine how newborns who are biologically unstable, neurologically immature or dysfunctional, or convalescing pre-term or post-term, deal with sensory input. Therefore, attempts to provide

sensory-motor therapies to infants in intensive care units should be delayed until carefully documented research studies designed by qualified investigators prove the value of these approaches. The ways in which intensive care practices facilitate or inhibit the infant's self-organizing capacity to maintain internal control should be the focus of these investigations.

Unproven intervention practices should not be utilized on ill or otherwise health vulnerable infants until the efficacy of these practices has been documented, and only after it is proven that these practices do not actually interfere adversely with the infant's health recovery. Model programs for early intervention in hospital based units should not introduce educational interventions and sensory-motor stimulation techniques until the infant has achieved physiological and physical stability and all interventions should be under strict medical supervision.

There is considerable variation among the states in the types of early intervention programs offered. Important factors for determining the scope and organization of program services include availability of funding sources, community support and the availability of the appropriate professional resources.

The Maternal and Child Health and Crippled Children's Services Program have had a major role in promulgating the philosophies of prevention, early indentification and intervention, particularly for high-risk individuals, and continue to place emphasis on a developmental model of interdisciplinary comprehensive health care in a family centered context. Significant federal funding support is provided through the Title V programs for activities specifically related to the high-risk infant.

The Office for Maternal and Child Health also supports a variety of research and training projects which provide for the training of various disciplines to upgrade assessment and intervention skills and to support research on intervention strategies. With the development of many new intervention programs for high-risk infants, including infants with handicaps, by non-health agencies, it is crucial that the state agenices responsible for maternal and child health and crippled children's services take leadership in addressing the health needs of this group of infants.

III. STATE OF ART PAPERS

INFANCY, WHAT WE KNOW AND WHAT WE NEED TO KNOW AS A BASIS FOR INTERVENTION

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Preparation of this address and the author's research reported herein was supported by the W.T. Grant Foundation, the Boys Town Center of Youth Development at Stanford, the Distribution Fund and Grant RR-81 from the General Clinical Research Center's Program of the division of Human Resources, National Institutes of Health.

In addressing the issue of what we know and what we need to know as a basis for intervention, I will mostly present evidence from research on very young infants. Much of what I will discuss will have implications for older infants as well. I will begin with what we know about the newborn's behavioral repertoire. I will then discuss the implications of our recent discoveries, both for the optimal care of young infants and for identifying risk of developmental problems that may be attenuated by early intervention. I will then turn to the special problems of infants born prematurely, as these children are at the highest risk for developing neurobehavioral deficits. In reviewing the strategies of intervention with these children and their parents, data from our own studies and those of others will be presented. Throughout, I will point to the issues and questions that need to be resolved, if we are to make progress in the field of primary prevention and early intervention.

As I will outline in broad strokes, the recent research evidence on the behavioral repertoire of newborns has shown that neonates are much more competent than had been assumed. Not long ago, it was thought that the newborn could neither see nor hear to any extent, a view still prevalent among parents. Research with neonates has demonstrated that newborns are not only able to fixate visually on objects from a certain distance, but are capable of pursuing objects when they are in the right state (i.e., Barton, et al., 1971; Korner, 1970; Wolff and White, 1965). Newborns also respond to differences in brightness. More remarkably, neonates show a preference among visual stimuli as judged by their consistently longer fixation of certain configurations than of others (Fantz, 1964, Hershenson, et al., 1965). Most interesting from an evolutionary point of view is Fantz's finding that infants less than 48 hours old look significantly longer at a picture with a stimulus configuration of a human face than at any other visual stimulus he tested.

Neonates are also highly responsive to auditory stimuli. When in the right state, they turn their eyes and heads towards the source of sounds (Brazelton, 1973; Wolff, 1959). As is the case with the visual modality, the newborn responds differentially to sound, depending on its stimulus configuration. From Eisenberg's (1965) carefully controlled studies, it appears that the newborn is most responsive to sound within the human speech range. Interestingly enough, the newborn appears to be programmed to respond more readily to the female than the male voice (Brazelton, 1970). By four weeks of age, the infant is so sensitive to minor differences in speech sounds that he orients to the change of a consonant after being habituated to another (Eimas, et al., 1971).

Newborns are responsive not only to visual and auditory stimuli, but they respond to contact and even more to movement stimulation. Crying infants predictably become alert to the environment when put in the upright position or moved about in other ways (Korner and Thoman, 1970; Greg, et al., 1976).

Newborns are also quite skilled at hand-to-mouth coordination (Hendry and Kesson, 1964; Wolff, 1966; Korner, et al., 1968). The infant touches his mouth significantly more often than his face, even though the face represents a much larger surface, and persists in maintaining this contact. Thus hand-mouth coordination is a well organized congenital behavior pattern (Korner and

Kraemer, 1972). The infant thus is from the start well equipped to engage in self-comforting behavior.

The newborn and the one-month-old infant already are hungry for stimulation. Infants at this age will modify their sucking rates in order to hear music or to see certain visual stimuli (Siqueland, 1969; Butterfield and Siperstein, 1972).

To me, these findings have two major implications: For one, the young infant is sufficiently differentiated in his behavioral response repertoire to benefit from more than mere physical care. The findings also suggest that, one by one, the forms of stimulation to which infants are most responsive are the very ones that an adequate and sensitive mother inadvertently provides in the course of infant care. To illustrate, in talking to her baby, the mother makes the very speech sounds that infants are so responsive to. In her caretaking activities, she not only represents a continuously moving visual stimulus, but she also, by picking up the baby, provides it with a good deal of movement stimulation. In their experimental studies, the researchers thus have unwittingly found that those stimulus components to which young infants are most responsive are the very ones that are inherent in the mother and her care. In evolutionary terms, the research findings make good sense: The infant is most tuned to those stimuli emanating from the very person on whose care his survival is most dependent. In practical terms, the research findings indicate, to me at least, that adequate maternal care during the first few months is a rich and sufficient source of sensory stimulation and perceptual experience for the average infant.

The situation is quite different for infants with special difficulties or mothers whose care is wanting for one reason or another. Difficulties can manifest themselves in babies in many different ways, ranging from extremes in temperamental disposition to physical and mental deficits. We need to learn to diagnose the latter at an earlier time, so that remedial programs can be instituted promptly. This is particularly true in the case of cerebral palsy.

Temperamental differences among babies seem to start early, judging from our studies of individual differences at birth (Korner, 1971, 1980). We postulate that these differences are largely based on individual differences in CNS functioning, expressed particularly in differences in sensory threshold levels and in the precursors of inhibitory mechanisms that regulate levels of excitation. A great deal more needs to be learned in this area, not only for the sake of our basic understanding of the origins of temperamental differences, but also for intervening appropriately with different children. To function optimally, hyperactive or hypersensitive infants require entirely different approaches than do withdrawn or timid children or infants whose sensory thresholds are very high.

We know from the New York Longitudinal Study (Thomas, et al., 1968) that infants characterized as "difficult" by virtue of their very high or very low activity level, the irregularity of their biological functions, the intensity of their reactions, their frequent expression of negative mood, and their slowness to adapt to change and new experiences, were prone to develop behavior

disorders later on. However, not all children, who as infants had constellations of these temperamental characteristics, developed these problems. A great deal depended on the flexibility and skill of the parents in dealing with these children.

There has been much controversy about whether intervention should be directed to the child or the parents, particularly the mother. While some infants obviously require direct professional help, much can be accomplished by helping mothers help their babies. Bronfenbrenner (1975), in a review of the effectiveness of early intervention programs, reported that with center-based programs, greater progress could be demonstrated at the end of the intervention year than with home programs. However, when the children were tested three years later, those who had participated in the home intervention program showed greater gains. Studies such as Beckwith's (1976) and Clarke-Stewart's (1975) underscore the importance of the quality of the mother-infant interaction on early child development. Thus, to achieve lasting gains, it makes sense to work through the primary caregiver of the child. Depending on the specific needs of the situation, this can be done by teaching relevant skills to mothers, by professionals or paraprofessionals acting as models for identification in dealing with the child, or by providing emotional and, in some cases, material support to mothers. Perhaps, in cases of severe maternal deprivation and depletion, "mother-care" may be the best way to achieve better infant care.

What We Know and What We Need to Know About Preterm Infants for Rational Intervention

I would now like to shift to the special problems of prematurely born infants, because these children constitute a large part of the population at risk for developing medical and developmental problems.

Unlike the mothers of full-term infants, the preterm infant's mother, no matter how capable, is obviously not a sufficient source of adequate care. Most preterm infants require prolonged hospitalization with all of the medical support that this environment offers. The mother's premature parenthood, her separation from her baby, and the resultant alienation she frequently experiences from her parenting role, as well as the infant's behavioral immaturity, not to mention the infant's medical problems, stunt, at least temporarily, her natural maternal inclinations.

What do we know about the behavioral repertoire of the preterm infant at various postconceptional ages? Sleep research with preterm infants has shown that, while prior to 32 weeks postconceptional age, it is difficult to distinguish from polygraphic records whether the baby is asleep or awake, with increasing postconceptional age, distinct sleep and waking states begin to emerge (Dreyfus-Brisac, 1970). We know that the younger the infants, the less tone they have and that the development of adequate tone is one of the best signs of progress. We also know that the preterm infant's motility is erratic, unmodulated and jerky, and that even after term, these infants tend to be more restless and irritable than full-terms. Evidence is accumulating that infants of about 34 weeks conceptional age begin to attend environmental stimuli,

including the human voice and face. However, this attention is qualitatively quite different from that of the full-term in that the preterm infant's gaze is fleeting and unsparkling on the one hand, and obligatory and perseverative on the other. When preterm infants at term are compared with full-term infants, the preterm infant's behavioral responses have been variously described as tending to be disorganized, uneven, obligatory, and/or weak (Dreyfus-Brisac, 1974; Parmelee, 1975; Sigman, et al., 1977; Howard, et al., 1976).

At later ages, the literature shows conflicting evidence regarding the functioning of children born prematurely. There are indications that the majority of preterm infants do not function subnormally on developmental tests, especially when the children's chronological ages are corrected for the gestational ages at which they were born (e.g., Hunt and Rhodes, 1977). Increasingly, however, follow-up studies bring to light subtle differences in functioning of these children, even though I.Q. scores may be within the normal or low normal range. These deficiencies include poor motor performance (Sistek, et al., 1979), signs of minimal brain damage as expressed in perceptual and visual deviations (Kaputo, et al., 1979), and deficits in hearing and language production (Field, et al., 1979). It is also becoming increasingly clear that prematurity in itself is not as damaging as the severe medical complications that attend it. In fact, Sostek, et al. (1979) reported that, in contrast to preterm infants who had major medical complications, premature babies who had an uncomplicated hospital course, did not show developmental delays or disabilities on later follow-up. What's more, small healthy preterm infants do not necessarily fare worse than healthy preterms born at older gestational ages, according to Sostek and others. There seems to be consensus that preterm infants whose later functioning is most affected are those who suffered intracranial hemorrhages or other CNS damage and infants who had severe RDS requiring prolonged ventilatory care (Fitzhardinge, et al., 1976; Field, et al., 1979; Marriage and Davies, 1977). With the advent of tomography and other sophisticated differential diagnostic techniques, it may become possible to predict much better than now, which perinatal complications lead to what kinds of consequences. Such prediction would be of tremendous help for medical planning, for instituting intervention or remediation programs and for dealing realistically with parental expectations.

Now let us turn to intervention. What do we know and what do we need to learn? Since much of the clinical and research evidence suggests that the most disruptive influences to the preterm infant's development are the medical complications attending prematurity, the greatest progress will come when neonatology will further improve the treatment of severe RDS and will better understand the mechanisms underlying intracranial bleeds. Neonatology is one of the fastest moving fields in medicine so that there is great hope for real progress. In addition to the major illnesses attending prematurity, the environment in which the young preterm is kept alive is likely to have a further disruptive influence on the natural course of the infant's maturation. A good deal of work has to be done in this area also.

Intensive care nurseries have alternately been described as environments of sensory deprivation and sensory bombardment. A good case can be made for both assertions. The sheer monotony of light and sound, and the lack of patterned stimulation in the nursery have been viewed as an environment of

sensory deprivation, while the intensity and persistence of these stimuli have been described as a source of sensory bombardment. Probably most cogent is the fact that in this environment, the infants do not receive the kind of patterned stimulation that is relevant to the stage of their neurophysiological development and that contingently reinforces the developing organization of the infant's biological rhythms.

Let us consider for a moment the kind of support system the uterus provides and what tasks the preterm faces by being born prematurely. Very suddenly, the infant is forced to cope with vital functions which the maternal organism normally assumes for him. The prematurely born infant is called upon to regulate his own temperature, to breathe on his own, to cope with the impact of gravity and to maintain his nutritional requirements by food intake through the gastrointestinal tract. In general, when an organism is called upon to function at a level for which he is unprepared, his attempts either collapse or he precociously manages to function, but at the expense of tremendous stress. Both occur in the preterm infant's struggle for survival.

In addition to the stresses attending the forced premature physiological functioning of the preterm, he is deprived of all of the sensory stimuli and experiences which attend intrauterine life. From an evolutionary point of view, it seems reasonable to assume that these sensory experiences are conducive to facilitating the normal growth and development of the infant. In particular, the preterm infant is deprived of the regulatory influences of maternal biological rhythms, which may be one of the contributing factors to why the preterm infant's behavior is so disorganized (Dreyfus-Brisac, 1974; Korner, 1979). Sterman (1967), for example, demonstrated a significant relation between maternal sleep stages and intrauterine fetal activity. The premature physical separation between mother and child abruptly disrupts these earliest forms of interaction. Perhaps, in planning our intervention studies with preterm infants, we can learn something from Hofer's studies with rodents. Hofer (1975a) found that rat pups separated from their mothers showed fragmentation in the organization and rhythmicity of their sleep patterns and a reduced cycle length. In another study by Hofer (1975b), separation from the mother produced behavioral hyperactivity in young rats. This was reduced to the level of non-separated pups by external stimulation over a variety of sensory pathways with a time patterning similar to the mother's periodic stimulation. Hofer concluded from his research that perhaps the "rhythmicity of maternal behavior acts as a 'Zeitgeber', or rhythm giver for the infants." Such a "Zeitgeber" from mother to child is clearly missing when an infant is born prematurely.

It is urgent to determine what ecological changes can be made within the limits of the intensive care requirements that would make the environment in which preterm infants grow to term more natural and more conducive to their growth and development. Even though many in-hospital intervention studies have been done that shed some light on this question, we have as yet no definitive answers about how much and what kind of stimulation is beneficial to preterm infants. As a result of several recent studies (e.g., Korones, 1976; Long, et al., 1980), investigators and clinicians alike have become concerned whether the continuous medical and caregiving ministrations in the intensive care nursery give preterms sufficient opportunity to rest. This concern is

well voiced in a recent editorial by Lucey (1977) entitled "Is Intensive Care Becoming Too Intensive?"

Barnard, Brazelton and Heidelise Als have warned us through the years that we must become alert to the infant's signals of distress and of sensory overload. Signs of distress include color changes, apnea and bradycardia, vomiting, and, in older babies, gaze aversion. Peter Gorski (1980), a former student of Brazelton's, recently presented a paper on this subject, which contained a fascinating anecdote. Dr. Gorski was consulted about a preterm infant with chronic lung disease who failed to thrive and who was scheduled for a gastrostomy so that the infant could be fed through its stomach. After lengthy observaton, Dr. Gorski recommended that surgery be postponed for a week. He observed that one nurse was singularly effective in feeding this baby, and he learned from talking with her that she disliked this infant. Unlike the other nurses who tried over and over again to interact with this infant, this nurse avoided contact with the baby, held the bottle inside the incubator for the obligatory ten-minute feeds and avoided looking at the infant. She was the only person on the staff who successfully could feed this baby and was able to avoid the vomiting and aspirates usually associated with his feeds. Dr. Gorski also noted that when held close by his father, this baby gaze-averted, his respiratory rate increased, and his color changed. By assigning this overly sensitive baby to a non-stimulating nurse, weight gain was accomplished and surgery avoided.

In accordance with his observations on the risks of sensorily overloading preterm infants, Dr. Gorski (1980) advised that multiple caregiving interventions, administered in rapid succession, should be avoided. Instead, these ministrations should be staggered to give the infant a chance to recover between procedures. In line with these considerations, it may also be fruitful to determine whether some of the traditional routine nursing procedures given every 2 or 3 hours could be reduced in frequency without jeopardizing the infant's care. Controlled studies are urgently needed in this area.

I hope that our growing awareness that infants can suffer sensory overload from our ministrations and our love and care will not send us back to the days of minimal handling of preterm infants. The intensive care nursery, in addition to being an environment that bombards the senses, is, by virtue of the monotony and noncontingency of its stimulation, also an environment of sensory deprivation. To make this environment more supportive of the infant's growth and development, we urgently need to acquire basic knowledge about conceptional age norms and about the range of individual differences in the preterm infant's capacity to tolerate and to profit from sensory input.

So far, I have only dealt with the amount and not the kind of stimulation that might be beneficial to preterm infants. Intervention studies have used many different forms of stimulation to offset the monotony of sensory input in intensive care nurseries. The choice of modality of stimulation largely reflects the philosophy and the implicit or explicit goals of intervention of different investigators. Some investigators have provided visual, auditory and social stimulation, all forms of stimuli to which full-term infants are highly responsive and to which preterm infants of various postconceptional ages <u>begin</u> to

respond (Katz, 1971; Segall, 1972; Scarr-Salapatek and Williams, 1973; Williams and Scarr, 1971). Since these forms of stimulation are part of the normal environment of full-terms, the implicit or explicit goal of these interventions is an attempt to accelerate the development of preterm infants. Other investigators have chosen to impart types of patterned stimulation which are prevalent in utero to compensate for an experiential deficit (Barnard, 1972; Freedman, et al., 1966; Korner, et al., 1975, 1978; Korner, 1979; Neal, 1967). Each of these investigators has used a form of vestibular-proprioceptive or movement stimulation as the main type of patterned stimulation for preterm infants.

It is of interest that, judging from the reviews on this subject by Cornell and Gottfried (1976) and by Masi (1979), preterm infants seem to derive benefits from most forms of supplemental stimulation. Several studies reported increased weight gain of the stimulated group of preterms as compared to a control group (e.g. Freedman, et al., 1966; Kramer and Pierpont, 1976; Neal, 1968). Hospital intervention studies have also shown increases in the sensory responsiveness of stimulated preterm infants (Katz, 1971; Neal, 1968; Segall, 1972). In terms of the development of the central nervous system, it is of theoretical interest that sensory stimulation in one modality can transfer to gains in another. Neal (1968), for example, provided a regimen of vestibular-proprioceptive stimulation to preterm infants and increased their auditory and visual performance. Supplemental stimulation given to preterms has also resulted in diminished irritability and in other changes in infant state behavior (Hasselmeyer, 1964; Barnard, 1972). Barnard, for example, found that infants placed in an intermittently rocking incubator had longer and more sustained quiet sleep epochs than controls.

The underlying mechanisms of the stimulation effects are still quite unclear. Relevant might be Denenberg's (1975) assertion that stimulus variation, rather than sensory constancy, is an important, if not necessary condition for adequate development. If stimulus variation introduced into the sensorily monotonous intensive care nursery is the primary beneficial factor, then it would not matter what form of stimulation is used. This obviously is not the whole story since the types of effects achieved in the different studies are not uniform.

My own work of intervention with preterm infants is governed by several theoretical considerations which made ontogenetic and clinical sense to me. My goal is to compensate for an experiential deficit brought about by the premature birth of the infant and to consolidate rather than accelerate development by providing developmentally relevant forms of stimulation. On the basis of considerable empirical evidence from our earlier studies with human infants and rat pups (Korner and Grobstein, 1966; Korner and Thoman, 1970, 1972; Thoman and Korner, 1971; Gregg, et al., 1976), which pointed to the fundamental importance of movement stimulation for very early development, we decided to provide such stimulation to preterm infants through waterbed flotation. The waterbeds which were developed in our laboratory oscillate very gently either intermittently or continuously in the temporal patterning of maternal biological rhythms. To date, we have found that the continuously oscillating waterbed significantly reduces apnea and bradycardia in infants with a diagnosis of apnea of prematurity (Korner, et al., 1975; 1978). We recently completed a study of the sleep of preterm infants on and off intermittently oscillating waterbeds, and indications

are, just as in Barnard's (1972) study, that quiet sleep was sustained longer in the experimental condition. We are currently trying to find out whether or not the neurobehavioral development of infants can be improved as a function of waterbed flotation. Clinical indications are that the fluid support provided by the waterbed preserves the fragile skin of very small preterm infants and alleviates the discomfort associated with conditions such as spina bifida, disseminated herpes, etc.

So far, I have mostly described intervention that is a separate enterprise from the routine care given preterm infants. There are also forms of intervention that involve changes in the care of preterms that hold great promise. Simply changing the infant's positioning at intervals from supine to prone has beneficial effects. According to Martin, et al. (1979), quiet sleep significantly increases when infants are placed in the prone, and oxygenation improves significantly in that and other states as measured by a transcutaneous oxymeter. Brazelton (1979) recently suggested that older, stable preterm infants should be fed not so much by the clock, but somewhat on demand. Brazelton, and Barnard as well, observed that when awakened from a deep sleep, preterms do not feed as well as when they are in higher states of arousal. When the busy nurses objected that they could not watch the state of the babies that closely, Brazelton suggested that they attach a bell to one of the infant's limbs which would ring as they became more active. I hope that a controlled study is under way to determine whether feedings contingent on the infant's state, by having them ring for service, will increase their weight gain, as well as their behavioral organization. Gene Anderson, et al. (1980) is doing very interesting work offering preterm infants, including those on ventilators, opportunities for non-nutritive sucking. Judging from the literature on the organizing effects of sucking, it would not be surprising if this type of intervention would prove to have highly beneficial effects.

In sum then, a lot of exciting work is going on in the area of intervention with preterm infants. We are beginning to know that most intervention has beneficial effects, but we do not know the underlying mechanisms that are instrumental. Perhaps, in the near future we will know what types of intervention will bring about what types of changes, but so far, no coherent picture has emerged that sheds light on this important question. Most of the research done has utilized multimodal forms of stimulation: Infants were rocked, held, and were given, in addition, extra visual and auditory stimulation. While this approach worked well empirically, we will never know what exactly brought about the effect. The use of only one form of stimulation at a time would not only reveal which forms of stimulation are ontogenetically the most relevant and potent, but would enable us to test some basic hypotheses regarding the chronology of maturation of the different sensory response systems. In practical terms, such an endeavor would eventually lead to a rational approach for deciding which forms of stimulation are the most relevant at any given postconceptional age.

Interventions With Parents of Preterm Infants

Let us now briefly turn to what we know and what we need to know about intervention with the parents of preterms. An unexpected premature birth almost invariably represents a major crisis for the infant's mother, associated with shock, bewilderment, helplessness and anxiety. I never cease to be amazed

how easily most parents of sick preterm infants give consent for study without asking questions. To get truly informed consent, we are the ones who raise questions regarding procedural issues to make sure that we are explicit about what we are going to do. I think this lack of inquisitiveness on the parents' part is a reflection of their state of shock that leaves no energy for appropriate questions.

We know from several studies that parents are helped a great deal when encouraged to visit the nursery and get acquainted with their infants by handling and caressing them, and helping to take care of them (Barnett, et al., 1970; Klaus and Kennell, 1976). This change in nursery care makes complete clinical sense in that it reduces the alienation from parenthood brought about by the separation from the baby. It diminishes the helplessness of not being able to do anything for the infant and it increases parental self-confidence in caring for the baby later on (Seashore, et al., 1973). And yet, our new-found knowledge should not lead us to insist that all parents must soon after birth begin to handle their baby. The sight of a tiny critically ill premie can be such a shock to parents that our encouragement to handle the baby may have counter-productive effects. In trying to help parents, we should not have universal expectations and should respect their individual ways of coping with the situation.

Another crisis may arise shortly before, or at the time of the baby's discharge from the hospital when parents are called upon to take charge of their infant's care. Much can be done to ease this transition. Individual instructions by nurses and parent groups can do a great deal to put the parents at ease and to help them cope. Some hospitals even provide rooming-in facilities in which parents can learn to care for their child with help close at hand. Clinically, there seems very little doubt that these interventions are of help. However, it would be useful to prove this point through controlled randomized studies.

Once at home, the parents face an infant that is usually more difficult to care for and who is less rewarding than full-term babies. Two studies have shown that in interaction with their mothers, preterm infants are less alert, less responsive, more gaze averting and irritable, less consolable, and more difficult to feed than full-term babies (Brown and Bakeman, in press; Field, 1979). It is no coincidence that studies have shown that preterm infants are over-represented among cases of child abuse (Elmer and Gregg, 1967; Klein and Stern, 1971). If the mother is to keep perspective during the first few months at home, it is important that she receive as much support as possible from the father, friends, extended family, visiting nurses, or other available support systems.

A Note on the Follow-Up of Intervention

I would like to conclude with a brief comment about the issue of short and long-range effects of intervention. The enduring effects and usefulness of early intervention have recently been questioned. It is as if the ultimate test of the cost effectiveness of early intervention rests on the long-term, measurable persistence of its effects. To me, this view is quite unrealistic,

particularly if there are no provisions for follow-through, post-intervention, aimed at maintaining the gains made. We know from the research of Sameroff and Chandler (1975) and of others that socioeconomic background and familial circumstances have an overriding influence on developmental outcome. Even though there is agreement that these environmental influences will obscure the effects of early intervention, there is, nevertheless, the unrealistic expectation that unless a persistent, long-range measurable effect is demonstrable, intervention may not be worth doing. A more realistic goal would be to strive to produce a better functioning infant and/or a more growth-facilitating parent-infant relationship at the time of intervention. Such gains would make the family more capable of coping with subsequent events, no matter what their nature. Under continued favorable circumstances this would also enable the family to consolidate and build on the gains that were made <u>during</u> intervention. I would think that these goals in and of themselves are sufficient reason to do and to support early intervention.

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III. STATE OF ART PAPERS

CHILD CHANGE IN AN EARLY INTERVENTION PROGRAM FOR THE DEVELOPMENTALLY DISABLED

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INTRODUCTION

There are three general categories of infants who can be considered at-risk for future developmental problems -- the medically-at-risk infant, the environmentally disadvantaged infant, and the infant who has sensory, motor, and/or mental disabilities. The overlap among these groups is significant. The following discussion will elaborate on current knowledge regarding the influence of the environment on the outcome of such infants.

Medically-At-Risk Infants

In order to study early identification of medically-at-risk infants, A.H. Parmelee, Jr., M.D., and his colleagues at University of California at Los Angeles designed and tested an assessment system for designating infants as potentially at-risk for future disabilities (Parmelee, 1979). The assessments consisted of 14 measures of medical, neurological, neurophysiological, and infant behaviors and two home observations of caregiver interaction administered between birth and nine months of age. A medically recognized high risk group of infants - 126 pre-terms - were selected as the target group. Full-term control infants were also included.

General medical intervention was provided for all of the families. Since all of the mothers had suffered unusual pregnancies or deliveries and/or had newborn infants requiring special care, the normal process of mother-infant attachment was interrupted. Early contact of parents with their infants in the special care nursery was encouraged in order to help them deal realistically with their infant's health problems. A nurse and pediatrician team was assigned to each family while the infant was in the hospital. The team provided opportunities for the parents to discuss their feelings. There was opportunity for these discussions to be continued when the infant was discharged since this same doctor-nurse team provided medical care for the infant at least through the first two years.

Even though the parents had support from medical personnel at the time of the infant's discharge from the hospital, they felt inadequate to provide proper care for their infant whom they were likely to perceive as fragile and sick. They continued during the first four months to focus mainly on the welfare of their infants and their ability to provide adequate care for survival and normal physical development. It was only during the latter part of the first year parents focused more on their infant's behavioral development.

The results of this study pertinent to this discussion are as follows: The infants' medical problems measured in the prenatal, perinatal, and postnatal periods, considered singly or in a summary score, were not associated with developmental outcome at nine or 24 months of age. However, pediatric complications measured at four and nine months were related to later developmental performance. Thus, medical problems beyond the neonatal period appeared to have an adverse effect on the progress of the infant. Since recovery from neonatal events did not predict a clean bill of health, careful monitoring of an infant's health during the first year is indicated. Furthermore, since development is eventually depressed if the infant's medical problems continue, one can

speculate that if there is an educational support base for the parent during this period, enriched environmental opportunities can be encouraged during the infant's recovery phase.

Information pertaining to kinds of caregiver-infant interactions which promote optimal development were also noted. The kinds of environmental transactions that occurred between a caregiver and the infant accounted for variance in the child's development beyond that explained by social class and other marker variables. For instance, infants who spent more time in social interaction with their caregivers performed more adequately on a sensorimotor series and a Gesell test in the first year of life. Furthermore, increased social interaction during the first year of life predicted increased competence at age two, three, and five years, as measured by the Bayley tests and Stanford-Binet tests, whereas obstetrical and postnatal hazards by themselves were not predictive.

Dr. Parmelee concluded that the development of the medically-at-risk infant is as influenced by the social environment as is the normal infant. Therefore, prediction of developmental disabilities among medically-at-risk infants must include assessments of the interaction between infant and family as well as detailed information about family background and social supports.

Environmentally Disadvantaged Infant

Infants growing up in poverty, although they perform normally during the first two years of life, tend, as a group, to show a steady decline in IQ scores past the age of two. In 1979 the Longitudinal Consortium reported on a 15-year follow-up of findings from studies of low-income children who participated in experimental preschool intervention programs (Lazar and Darlington, 1979). The 18,568 children ranged in age from three months to five years when they entered the programs. 92% were black, 40% did not have fathers in their home, and 51% had three or more siblings. The average level of their mother's education was 10½ years. The settings for the 11 programs were of three types - six center-based, two home-based, and three combined center and home-based.

An analysis of the data by the Longitudinal Consortium produced the following conclusions. First, assignment to special education classes was significantly reduced in children who had attended early education programs, regardless of their initial abilities or early home backgrounds.

Second, early education programs reduced the number of children retained in grade, regardless of sex, ethnic background, early IQ, and home background. Third, the results of the achievement test scores when the children were in fourth grade indicated that early education significantly increased mathematics scores and suggested a trend toward increased scores on reading tests. Fourth, the intelligence test scores of the treated children were significantly higher up to three years after the preschool programs ended, and after that time, remained higher for some programs, but not others.

The last analysis of data that the Consortium reported compared the children's attitudes and values. As would be anticipated, children who had early education

experiences gave achievement-related reasons for being proud of themselves.

The eleven programs that participated in this study seemed equally effective in providing help to the treatment group of children. Whatever the programs' individual characteristics were, behavioral outcome of the children was favorable.

Developmentally Disabled Infant

The medical needs of the sick infant and the environmental needs of the low-income infant define the third group of children -- the developmentally disabled. Their medical problems are great, and they tend to live in an environment in which they frequently cannot initiate interaction nor respond to their caregivers' solicitations. The developmentally disabled infant is as deprived of meaningful transactions with its environment as is the normal child growing up in a disadvantaged environment.

Play is one way to enhance learning opportunities for young children. Bronfenbrenner,(1979, p. XVII), writes that "play is closely linked to the biological forces that impel, direct, and delineate action and growth." A feeling of competence emerges when a child is able to see consequences as a result of his spontaneous behavior. Furthermore, parents who participate with their children in elaborate play are rewarded by their efforts. Their children perform better on IQ tests. It has also been found that preschool children led in pretend play by an adult were more adept in their own pretend play. It is these experiences that developmentally disabled children are usually deprived of. Therefore, early intervention programs which encourage normal experiences with inanimate objects and social partners exist.

UCLA Intervention Program for Handicapped Children

The UCLA Intervention Program for Handicapped Children, affiliated with the Department of Pediatrics, Division of Child Development, provides coordinated medical, educational, and social support services to families with developmentally disabled children on a year-round basis. The multidisciplinary staff composed of early childhood educators, social workers, occupational, physical, and speech therapists works closely with the Medical Director, a pediatrician with subspecialty training in Child Development. The program provides home and center-based services.

The goals of the program are:

1. To help each parent gain confidence and competence in raising his child.
2. To develop each child's strengths to the maximum.
3. To help the child compensate as much as possible for his weaknesses.

The children are clustered according to chronological and/or developmental age into three subgroups: the young infant group, 0 to 9 months, the older infant group, 9 to 18 months, and the toddler group, 18 to 36 - 48 months. Non-handicapped children are integrated into the older infant and toddler groups.

A yearly follow-up program is available to all families after they transfer to community facilities.

The program is a training site for students from a variety of disciplines, including nursing, psychology, speech pathology, education, kinesiology, pediatrics, and child psychiatry. Research studying the social interaction between the handicapped and non-handicapped children, use of non-verbal communication systems with handicapped children in the under three year age group, and assessment of spontaneous play behaviors in the under three-year-old are current projects.

DATA ANALYSIS

There were 75 children who have been seen in our follow-up program from 1974 to the present. Most children entered the Intervention Program in the second year of life, 34% from ages 13 to 18 months, and 30% when aged 19 to 24 months. A small percentage, 18%, entered before a year of age, and a small percentage after 2 years of age, 19%.

A majority of the children in the program were diagnosed as cerebral palsy. Twenty-seven percent of the children in the program had cerebral palsy alone; an additional 23% of the children had cerebral palsy and associated mental retardation. The groups were differentiated on the basis of the adaptive, language, and personal/social items of the Gesell Scale which was administered to all children just prior to entrance into the program. The next largest group of children, 21%, were mentally retarded, primarily on the basis of Down's Syndrome. A small percentage of children in the group were visually handicapped or had a variety of neurological disorders. The group also contained three children diagnosed as autistic, and three diagnosed as developmentally delayed.

The families of the children were mainly middle-class with stable intact marriages. Of the 75 families, only 15 were divorced and five parents were single, never having married. Thirty-two of the children were the only child in the family. There were also 32 children in the program from two children families, most of them being the younger sibling. The other children came from three or more child families, including two sets of twins.

Most children stayed in the program two years. Some children (26%) stayed three or more years, and 20% stayed less than one year. Only four children stayed less than six months.

The children tended to remain in the program until the ages of three and three and one-half. A small percent (12%) left in the second year of life, and a small percent (18%) stayed past age four.

Health Components

The families asked for services from many other health personnel in addition to program staff and staff of Regional Centers (Table 1). During

the child's stay in the program, the families, on the average, sought out more than four other health personnel. Contacted were: private pediatricians, pediatric neurologists, child development specialists, cardiologists, ophthalmologists, gastroenterologists, cardiac surgeons, pediatric surgeons, ear, nose, and throat specialists, audiologists, endocrinologists, geneticists, orthopedic surgeons. The families' needs for medical services were almost overwhelming.

During the infancy and early childhood years, the acute health care needs were significantly higher than in later years. Diagnostic evaluations and specific medical treatment plans were essential in order to provide the developmentally disabled child a chance for optimum interaction with the environment. Seizure control, prevention of amblyopia, correction of hearing deficits, surgery to correct orthopedic problems such as dislocating hips, cardiac surgery to correct life threatening heart failure, genetics evaluations to determine if a hereditory factor had caused the disability were common problems. The primary care physician, usually a pediatrician, was frequently unable to coordinate the volume of medical information that the families received from the medical subspecialists.

It might have been preferable to have the primary care physician coordinate these situations. However, it is recognized that pediatricians require increased training in the evaluation of the developmentally disabled child. By having a health professional available and working closely with the educational staff of the Intervention Program, the families were able to focus on their child's total needs.

Gains in Mental Status During the Program

All children during their stay in the program were examined by the Gesell Schedules at six-month intervals. In addition, at yearly intervals after discharge from the program, the Peabody Picture Vocabulary Test was administered to those children with mental performance at least at a two and one-half year level. The Gesell scales were administered to those children who performed below the minimum mental age required for the Peabody Test. These test scores were used to evaluate the program's effect on cognitive growth.

As Table 2 illustrates, all but a very few children made gains in language performance during their first year in the program (Sign test, $p<.001$). The gains were particularly significant for children with cerebral palsy without associated mental retardation. In that group 74% increased their language skills markedly at a level of acquisition equivalent to that of normal children. Children with mental retardation made smaller gains.

Table 3 shows the changes achieved in personal/social items after one year in the program. Most children made significant gains in the personal/social area as they had in the language area (Sign test $p<.001$). A majority of children with cerebral palsy without mental retardation and even a sizeable minority of mentally retarded children were able to acquire personal/social skills equivalent to that of normal children.

TABLE 1

NUMBER OF HEALTH PROFESSIONALS USED BY EACH FAMILY

NOT INCLUDING PROGRAM STAFF AND REGIONAL CENTERS

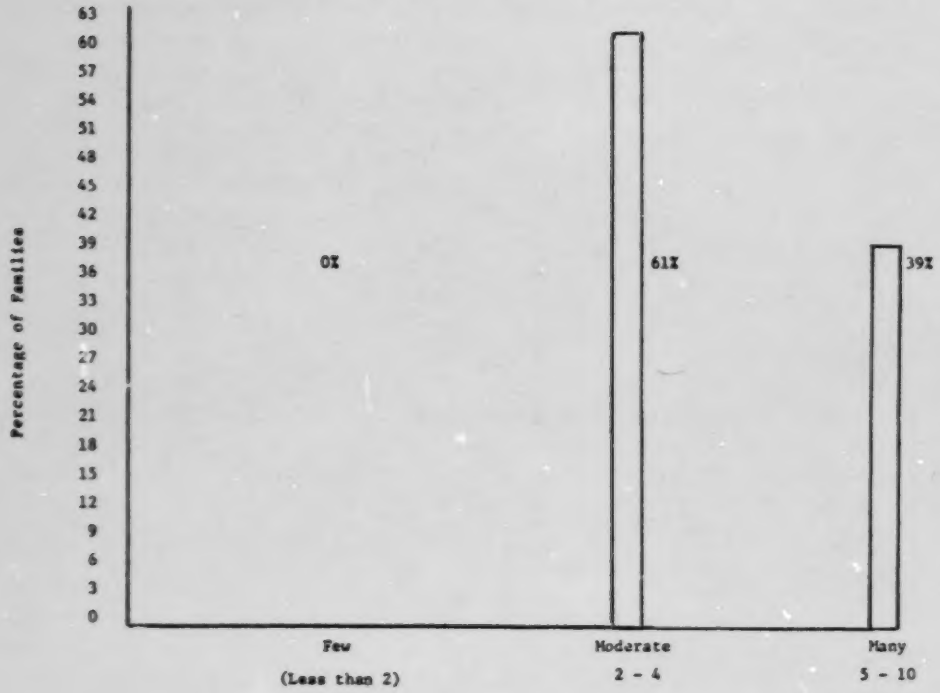
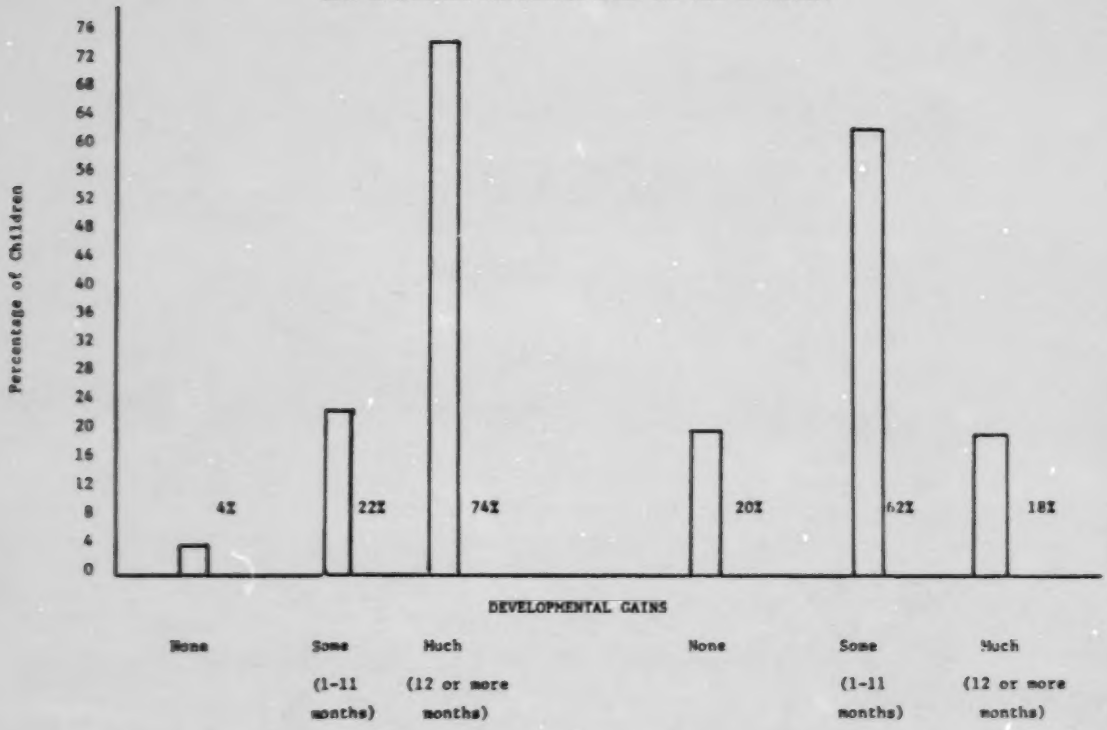


TABLE 2

GAIN IN LANGUAGE PERFORMANCE AFTER ONE YEAR IN PROGRAM



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In considering the above findings, we asked a further question. While it is clear that the children made gains in level of performance, did their rate of gain exceed their initial rate on entrance? Had attendance in the program increased the children's DQ scores, or had they declined or stayed the same as on entrance? Analyses indicate that somewhat less than half of the children without mental retardation, and one-third of the mentally retarded children made gains in language DQ (Table 4). A sizeable percentage, however, declined in DQ performance. There was, therefore, no statistical evidence that the program in that year had altered DQ scores in one or the other direction. Changes in rate of acquisition of personal/social skills showed a similar pattern, with more children making gains, and fewer declining (Table 5).

Changes in Mental Status One Year After the Program

Research evaluating early intervention with environmentally disadvantaged children usually finds that significant increases in IQ occur during the program, but are "washed out" later. In order to evaluate the stability of changes in DQ or IQ associated with our intervention, IQ scores one year after discharge were compared to IQ's at intake (Table 6). Children with cerebral palsy maintained, and even increased, their gains in IQ showing a statistically significant increment (Sign test, $p<.01$), whereas children with mental retardation tended to stay the same or progressively decline.

In sum, the rate of language and personal/social growth was accelerated for cerebral palsied children without mental retardation during our program and continued on follow-up. The rate of growth in our program for mentally retarded children showed a decline from infancy to later, a decline that increased after discharge from the program.

Social Competence

School placement and the need for special education services has proven to be a sensitive outcome measure of social adaptability in longitudinal studies of medically-at-risk infants as well as in follow-up studies of early intervention with environmentally deprived children. The successful social adaptations made by the children in our program were demonstrated by the fact that despite serious disabilities, half (48%) of the children were able to attend normal preschool and/or elementary schools (Table 7). The other half of the group needed special education classes. Only two children were placed in residential institutions; and only two children were kept at home.

Conclusion

The medically-at-risk infant, the environmentally disadvantaged infant, and the developmentally disabled infant show significant developmental progress when exposed to early caring, responsive environments. Focusing on the developmentally disabled infant, we find that during the first few years, there is a continual need for many medical evaluations and treatments in order to provide the infant with opportunities to relate to the environment through

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TABLE 3

GAIN IN PERSONAL/SOCIAL STATUS AFTER ONE YEAR IN PROGRAM

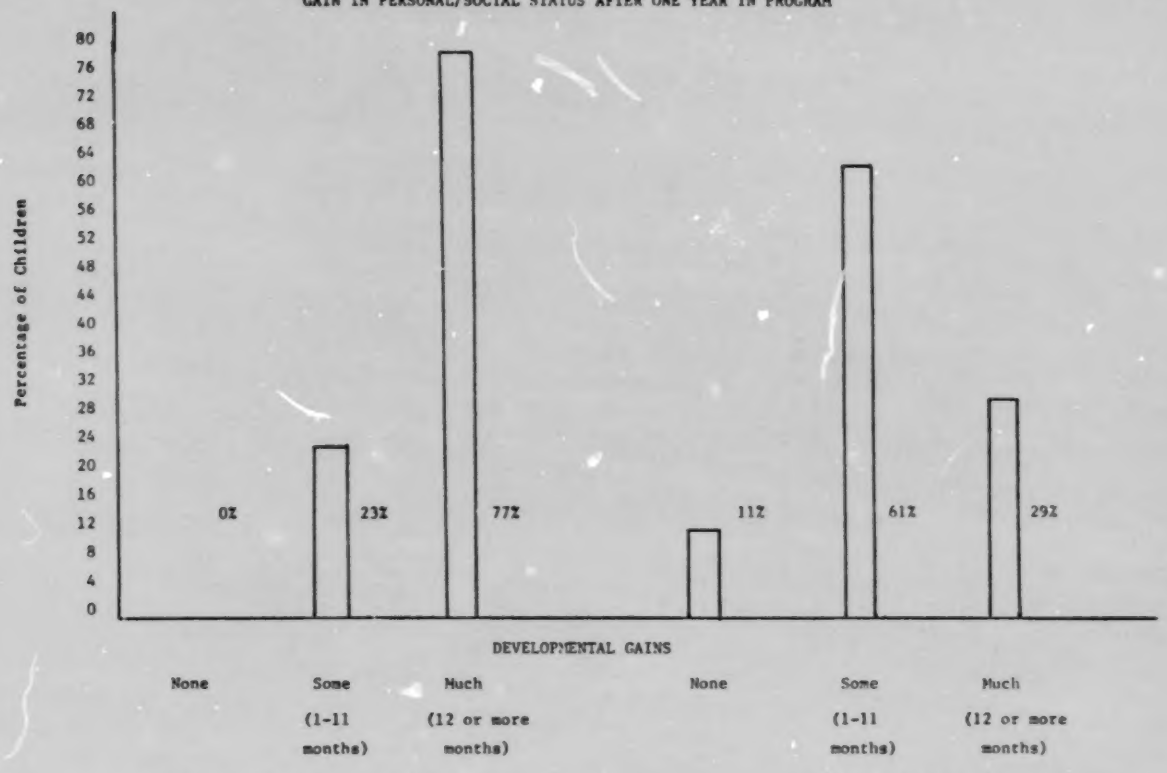

TABLE 4

CHANGE IN RATE OF LANGUAGE ACQUISITION AFTER ONE YEAR IN PROGRAM

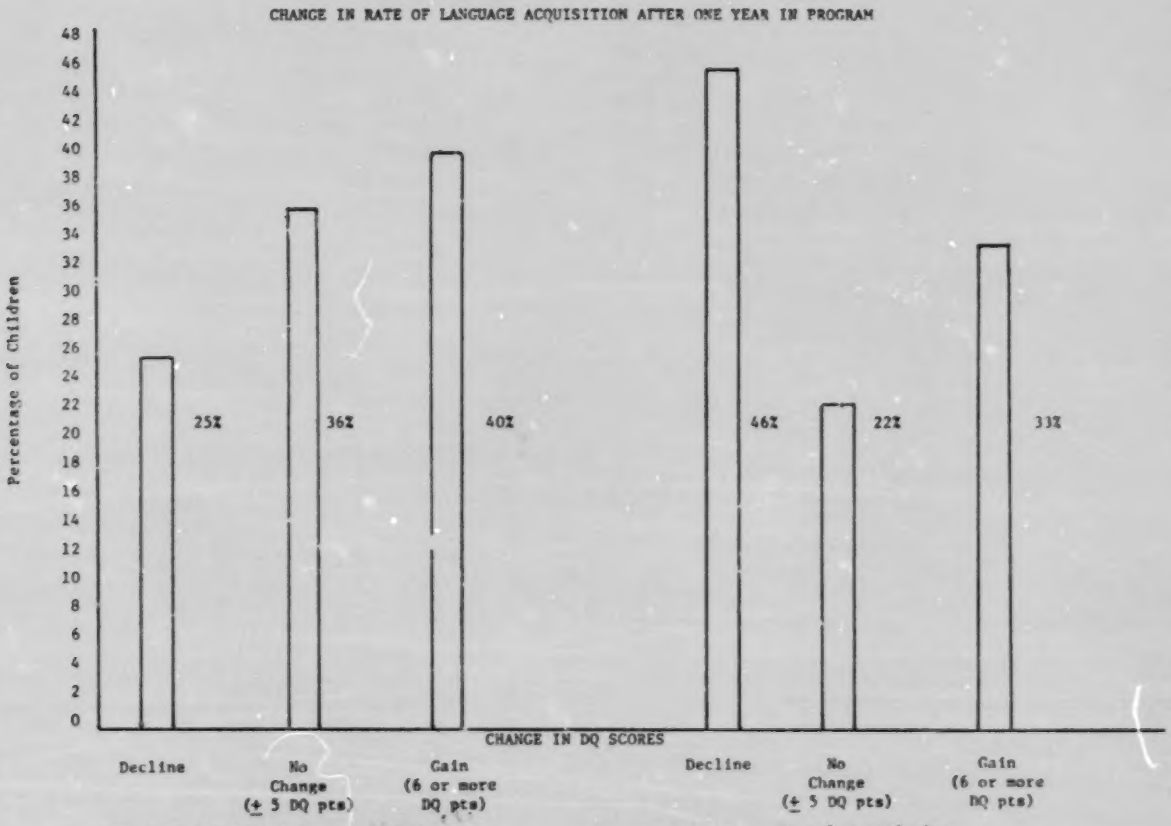

TABLE 5

CHANGE IN RATE OF PERSONAL/SOCIAL GROWTH AFTER ONE YEAR IN PROGRAM

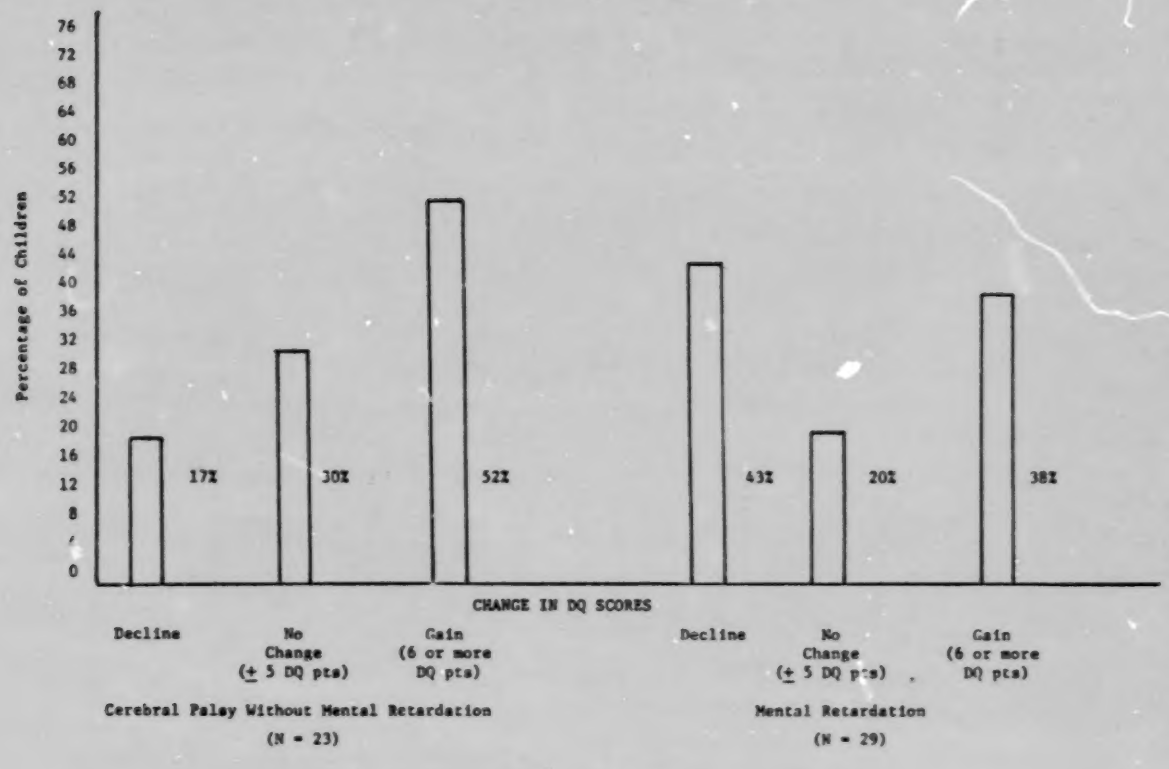

TABLE 6

CHANGE IN RATE OF LANGUAGE ACQUISITION FROM INTAKE TO ONE YEAR FOLLOW-UP

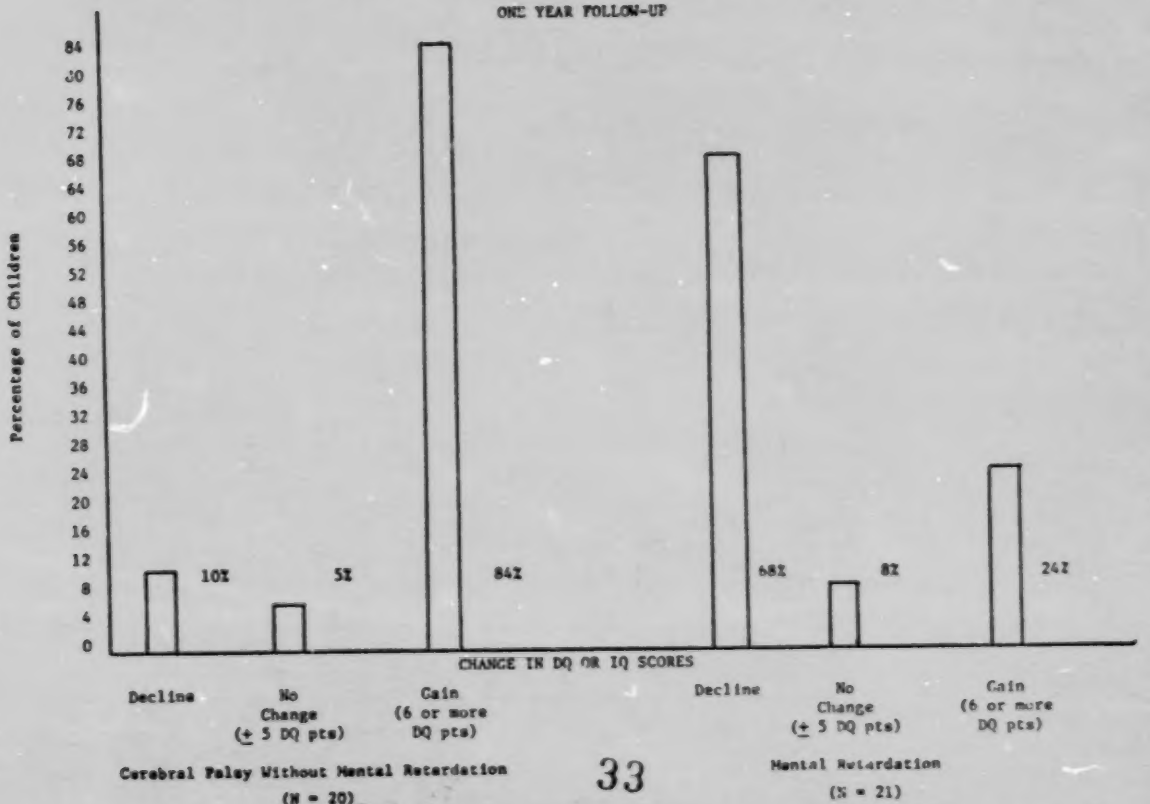

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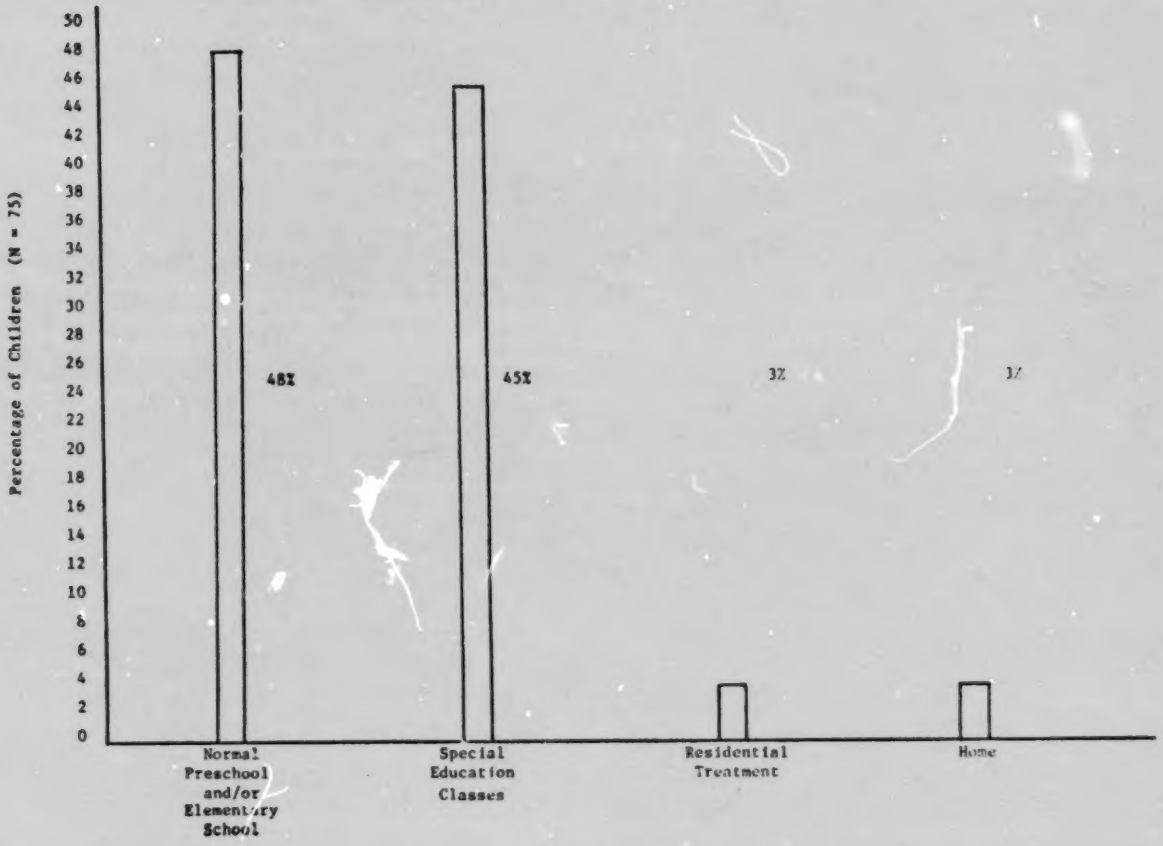
TABLE 7

SCHOOL PLACEMENT AFTER DISCHARGE FROM PROGRAM



better hearing, better vision, better opportunities for movement.

Concomitant with adequate health care supervision of the developmentally disabled infant, opportunities for enhancement of social, language, and cognitive skills need to be encouraged. Through early intervention programs families can begin to learn about the skills of their disabled child. Medical diagnosis and treatment plans are essential. However, there have to be occasions for parents to begin to shift from this as a primary focus and onto their child, the person. Thus, coordination between the medical and educational therapy systems is of utmost importance.

The fact that 50% of the children from the UCLA Intervention Program were able to enter normal classrooms at the time of discharge and that environmentally disadvantaged children with early educational experiences were successful in regular classrooms indicates that social abilities necessary for acceptance by the normal community are being fostered. Our developmental testing tools to date only partially reflect this ability.

The developmentally disabled infant cannot always make gains as recorded by our current developmental measures. However, increased skills in pretend play, independence, social competence in initiating and maintaining social interaction with others, and abilities to change task orientation are a few of the finer measures of change which need to be defined. Some of these areas are being examined in research with normal infants. For instance, we have reported about a representational play measure which can be used with children between nine and 30 months of age (Largo and Howard, 1979). It would be beneficial for the field to develop these kinds of measures as clinical tools.

There is very little that the medical profession can do to change the neurological status of the quadriplegic child or the global retardation of the Down's Syndrome child. However, once a medical diagnosis is made and available medical treatment programs initiated, it is the responsibility of professionals from health and educational fields to provide early assistance to the children and their families so that the handicapped child can obtain optimal experiences which promote social and cognitive development.

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III. STATE OF ART PAPERS

INFANT INTERVENTION:
PARENTAL CONSIDERATIONS

by

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and

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INTRODUCTION

Many intervention programs for infants who are handicapped or at risk have been developed in recent years. Although all of these programs share the common goal of optimal infant development, they approach this goal in a variety of ways. Some programs are home-based service delivery models, others are center-based, and others combine these two approaches. Programs also differ significantly with respect to the population they serve, their program philosophy, their specific goals and objectives, their curriculum, and the extent of parent involvement.

This paper focuses on the need for parental involvement in early intervention. After a review of the literature and current parent involvement efforts in early intervention, the paper discusses necessary components for designing and implementing a parent involvement program, and directions for the research.

I. REVIEW OF THE LITERATURE: THE NEED FOR PARENT INVOLVEMENT, AND CURRENT EFFORTS

The proliferation of widely differing infant intervention programs has prompted studies to assess their effectiveness. In a review of cross-sectional and longitudinal studies on the effectiveness of early intervention, Schaefer (1972) concluded that, of the programs he reviewed, those concentrating on involvement of the parents ("parent-based") were more successful in long term effectiveness. Even these effects diminished, over time, however, leading Schaefer to suggest the need for continued, long-term involvement with parents in order to maintain child gains. In another review, Bronfenbrenner (1975) reported that intervention is most effective when the program is home-based, begun when the child is very young, involves the parent directly in activities fostering the child's development, and encourages reciprocal interaction between the mother and child.

These conclusions that effective early intervention must include parent involvement are supported by research efforts demonstrating that the quality of the interaction between parents and infants is critical to infant development. As early as 1945 Spitz demonstrated convincingly that the primary caregiver significantly affects infant development. He studied groups of infants from four different environments and found that infants from an institutional setting did not function as well as infants from the other three environments. Spitz concluded that the critical difference between the institutional setting and the other environments was the lack of a mother-child relationship in the institution.

Six years later, Bowlby (1951) reviewed several studies on the effects of institutional care and confirmed Spitz's belief that the presence of a mother figure was crucial to infant development.

In an effort to understand how the caregiver-infant relationship affects later development, researchers in the past two decades have studied discrete elements in the interaction and their effect on child development. These studies

have shown that early interaction between the parents and infant affects the skill development of the child both immediately and later in life (see e.g. Lewis and Goldberg (1969), Yarrow, Ruberstein, and Pederson (1975), Wach's Uzgiris, and Hunt (1971), Tulkin and Kagan (1972), Barnard (1979), Stern, Caldwell, Hersher, Lipton, and Richmond (1973), Bell and Ainsworth (1972), Rubenstein (1967), and Yarrow, Ruberstein, Pederson, and Jankowski (1972).

Infant specialists recognize that the presence of a handicapping condition in infancy can complicate parent-infant interaction and jeopardize the successful functioning of the family unit. Olshansky (1962) refers to the common parental reaction to the birth of a mentally retarded child as "chronic sorrow," requiring continual adjustment in the parenting process. Drotar, Bashiewicz, Irvin, Kennell, and Klaus (1975) analyzed interviews with 20 parents to determine the course of parental reactions to the birth of a child with a congenital malformation. They identified five steps of parental reaction: shock, denial, sadness and anger, adaptation, and reorganization.

Klaus and Fanaroff (1973) cautioned doctors to anticipate maternal mourning for the loss of the perfect infant the mother had expected. They suggested that these feelings could interfere with the parent's ability to accept the child fully. They also urged doctors to communicate the findings about the child's condition several times. While in shock, parents have an impaired ability to recognize, evaluate, and adapt to reality.

Stone and Chesney (1978) reported that handicapped infants in their study vocalized late, seldom smiled, did not often establish eye contact with the person holding him/her, and had unusual patterns of postural adjustments to being handled. Stone (1979) specified that these patterns of behavior impact directly on the functioning of the mother-infant dyadic system, in that the usual biologically and culturally structured reciprocity between the behaviors of one and the responses of the other is disturbed. She listed the following six parent capabilities and explained how they could be altered when the baby is handicapped: 1. Alertness and responsiveness to the infant's communication of distress; 2. Alertness and responsiveness to the infant's state of arousal, combined with an awareness of the need to intervene when the infant spends protracted periods of time apparently not attending to stimuli in the environment; 3. Ability to hold the infant in a mutually enjoyable way; 4. Establishment of eye contact; 5. Communicating effectively; 6. Enjoyment of and effect for infant.

Several studies have attempted to isolate the impacts on interaction when the infant is handicapped by comparing the interaction between handicapped infants and their caregivers with the interaction between non-handicapped infants and their caregivers. (Marshall, Hogrenes, and Goldstein, 1973; Thoman Becker and Freise 1976; Jones, 1977; Vietze, Abernathy, Ashe, and Faulstich, 1978; and Buckhalt, Rutherford and Goldberg, 1978.) Tyler, Kogan and Turner (1974) reported on the results of a two-year study on interpersonal experiences among 10 cerebral palsy children, their mothers, and their therapists. Verbal and physical interactions were recorded and analyzed at 10-month intervals. Both mothers and children displayed greater amounts of negative affect during therapy sessions than during play sessions, and their simultaneous efforts to

compete for control of the situation suggested that the new experience was highly stressful. At the end of two years, therapy situations were still characterized by greater amounts of negative effect than in play sessions. Although mothers were more negative, they were not correspondingly less positive in therapy than in play. Mothers' displays of positive effect decreased significantly in all situations over time, and at the end of the study, mothers were displaying significantly less warmth than groups of comparison mothers. This study demonstrates the need to examine closely the effects of early intervention on parent-infant interaction.

Recently several lines of research at the University of Washington have examined parent-child interaction with handicapped infants. The first is a study by Kelly (1979) in which the parent and handicapped infant were observed during a teaching interaction. This baseline measure became a major programming determinant of the intervention. The study involved 14 handicapped infants and their caregivers who were stratified by infant age, 0-12 months and 13-18 months, and then randomly assigned to either a treatment or control group. Both groups were pre-tested and post-tested using an observational scale which recorded the frequency and duration of initiating and responding behaviors of the caregivers and the infants. These behaviors were also rated as being either positive or negative. The treatment group received a home-based intervention program designed to improve the quality of interaction between the infant and the caregiver and the control group received no intervention. After the intervention phase,the two groups were post-tested using the same observational schedule.

The data from the pre-tests and post-tests were compared using analysis of variance to determine the effectiveness of the intervention program. This comparison revealed that the frequency and duration of positive caregiver behaviors significantly increased as a result of treatment. Specifically, another finding was that the duration of controlling caregiver behaviors significantly decreased as a result of the treatment. It is important to note that these behaviors occurred in spite of relatively no changes in the frequency of infant behaviors. Therefore, through a program of orienting the parents to concentrate on encouraging the infant's behavior, it was shown that parents began to be more reinforcing of the child's behavior and less controlling. This study is important because as Tyler's work demonstrates the parent-child interaction with parents of handicapped children in therapeutic and educational sessions tends to deteriorate over time. Hence,this evidence that with guidance the parents can alter their response patterns without any appreciable short-term change in the child's behavior is very hopeful in terms of how we might work to effectively support the parent of a handicapped child.

The second study at the University of Washington has to do with premature infants and their parents. (Barnard, Gray, Wenner, 1979) The premature infant is less alert and responsive when compared with a full-term infant at the newborn period when matching for conceptual age. (Martin, 1977) Also when comparing the pre-term and full-term infant at one and four months of age during a teaching interaction, the pre-term infant is less alert and responsive. The teaching interaction allowed observation of parenting behaviors, and showed that at one and four months there was no difference in the pre-term and term

mothers' involvement and responsiveness with the child. However, by eight months the parents of the premature infant were less responsive to the infant in the teaching interaction. Specifically, the parents when observed in the teaching interaction were less sensitive to the cues of their infant, had less good timing, and were less reinforcing to the infants; whereas the infants, pre-term and term,were not showing differences.

In a related analysis of the same parent and infant groups, pre-terms and terms, in the feeding observation, there was a significant difference in the pre-term and term mothers and infants at both four and eight months. (Speitz, Syndan, Barnard, 1980 working draft) Generally, both the pre-term parent and the infant display less positive affect and less eye-to-eye contact with each other. Pre-term infants also smile and laugh less.

This data suggests that parent involvement with the handicapped or high risk infant is important, and maybe one of the more modifiable aspects of our treatment approaches with the hardicapped child. The goal of therapeutic intervention would be to alter the circumstance whereby the parent of a handicapped or high-risk child is not as strongly influenced by the lack of feedback from their child, and particularly the lack of positive affective feedback. With therapeutic support and guidance, the data suggests, the parents can maintain their positive input to the child.

One of the important tasks is to know more about what sustains parent involvement with their children. For the past nine years Barnard and Eyres (1979) have been involved in a study of parents and normal infants. The sample involved approximately 200 families with half of the mothers with high school or less schooling, and half with 13 or more years of schooling; half of the sample had complications during their pregnancy and half did not. Discoveries about the involvement and responsiveness of the major caregiver related to other factors about the infant and about the environment of the family may be instructive for our work with parents of handicapped children. Mothers who were more involved and responsive with their "normal" children had higher educational levels, reported higher father involvement during pregnancy, and had low or moderate life change. Mothers with good psychosocial assets, meaning that they felt good about themselves and about their supporting environment, were more involved with their children. The degree of parent mutuality also correlated with the mother's involvement and responsiveness with the child. The parents who agreed on matters of child rearing seemed to provide a different and more positive background for the mother's involvement. Finally, one important measure was whether or not the mother had a realistic expectation about the child's behavior. If the mother had realistic expectations, she had higher involvement and responsiveness with the child (Barnard, 1979).

Much of the literature focuses not only on the interaction of the parent-infant dyad, but also on the functioning of the entire family unit. Farber (1964) views the family as a set of mutually contingent careers. He defines "career" as a progression of roles that unfold in a patterned sequence in a life cycle. The birth of a child with a handicap eventually slows down the movement of this cycle. Farber (1968) states that the presence of a child with a severe hardicap can affect age and sex roles in the family, community relationships, and the social mobility of parents and siblings. Barnard and

Erickson (1976) outline the three different strategies of family organization described by Farber (1965) and stress the importance of the professional working within the family strategy, strengthening it and not imposing recommendations foreign to the family's orientation or method of problem solving. Gath (1979) reported the results of a longitudinal study to determine the effects of having a baby with Down's Syndrome in the family. She found that all parents experienced grief, and the effects of this are seen more in deterioration of their mutual relationships rather than in their individual health. Dunlap (1979) reported a study in which families with a disabled member had adjusted well and believed there had not been a significant effect on their family. At the same time these families reported that they were badly in need of supportive services that could ease some of the demands created by a handicapped person. Intervention efforts, therefore, must be designed to assess the needs of families and find adequate ways to provide services.

Meadow and Meadow (1971) subdivide the role of the parent of a handicapped child into two broad categories: the technical and the expressive. Examples of technical aspects include learning to help a cerebral palsied child use his muscles, or learning to help a deaf child adjust his hearing aid. Expressive aspects include learning to cope with the parent's own feelings of guilt and sorrow, or learning to cope with feelings of rejection or pity from neighbors. It is important for the helping professional to recognize the parents' expressive and technical roles. Parents who feel guilt and sorrow or experience grandparents' and friends' feelings of rejection or pity should be able to openly express these feelings in a supportive atmosphere. If a professional sends message of avoidance when a parent confides these feelings, a good parent-professional relationship based on trust and understanding could be jeopardized. At the same time, parents usually recognize the immediate needs of the child, and professionals must be prepared to provide information that helps parents deal with the technical role. The United Cerebral Palsy Collaborative Project (1977) published the following table giving diagnostic information on the infants in their project. It is apparent from Table 1 that many infants experience multiple problems. Parents need immediate information about the diagnosis, available treatment services, and their own role in helping their baby develop within their family unit.

Numerous other articles and books (Carver and Carver, 1972; Birenbaum, 1971; Gath, 1977; Schild, 1971; Fox, 1975; and Kratoville, 1975) are devoted to the importance of considering the needs of the entire family in intervention efforts.

Since 1968 federal legislation has mandated parental involvement in preschool projects for handicapped children funded by the Bureau of Education for the Handicapped (Wiegerink, Posante-Loro, and Bristol, 1978). This legislation for the Handicapped Children Early Education Program (HCEEP) requires that parents be encouraged to participate in the programs (PL 90-538, SEC 623). Over 300 programs receiving HCEEP support operate under regulations that require: 1) parent assistance in the planning, development, operation, and evaluation of the project; 2) parent training as a project component; 3) parent participation in educational and therapeutic components of the project; and 4) opportunity for

TABLE I: Diagnostic Categories of the First 1067 Children Enrolled in the National Collaborative Infant Project*

	From Original 5 Centers (N = 630) %	From Additional Centers (N = 437) %
Cerebral palsy	56.5	37.7
Minimal brain damage	25.5	26.6
Visual problems	33.7	27.7
No vision	4.8	4.6
Partial vision	11.9	9.8
? vision	17.0	13.3
Hearing problems	12.0	12.6
No hearing	1.4	0.7
Partial hearing	1.7	3.7
? hearing	8.9	8.2
Convulsions	16.0	23.1
Occasional	9.2	15.1
Frequent	6.8	8.0
Oral pharyngeal problems:	39.0	27.5
Feeding-definite problems	29.8	22.0
Speaking-questionable problems	9.2	5.5
Genetically determined conditions	18.1	31.4
Down's syndrome	10.2	22.9
Other	7.9	8.5

*The diagnostic categories are not mutually exclusive. The cerebral palsied and those considered minimally brain damaged, as well as those with genetically determined conditions, frequently showed visual, auditory, and seizure problems. Of the total, 76.2% were suspected of having some problem in development before the age of 6 months. About 40% entered the programs before they were 1 year of age, 60% by 18 months.

parents to advise and assist in information dissemination concerning the project.

The above review demonstrates the recognized need for parent involvement in intervention programs. Programs have responded to this need in several ways. Table II summarizes several programs and describes the major scope of their parent involvement components. As Table II demonstrates, these programs vary, not only according to service delivery models, target population, and major program goals, but they also vary significantly in the extent and the manner that they include parent involvement.

II. COMPONENTS FOR DESIGNING AND IMPLEMENTING A PARENT-BASED PROGRAM

In determining the extent and the manner of parent involvement in an infant intervention program, it is necessary to consider several related program elements:

A. The program goals including parent involvement
B. The initial and continual assessment of individual parent needs related to the goals
C. The activities developed to meet the individual needs of parents indicated by the assessments
D. Parent involvement in planning, decision making, evaluation, and dissemination

This section of the paper discusses these elements in more detail.

A. Parent Involvement Goals

While there is a legislative mandate that parents be involved in programs for atypical infants, and most programs feel they are approaching this mandate by involving parents in the program, we need to come to a better understanding of what the goals for parent involvement should be.

The Nationally Organized Collaborative Project (Haynes, 1976) contributed excellent ideas about programming for atypical infants and their families. In their monograph on Program Evaluation (Meisel, 1977) they described goals arrived at by starting with handicapped adults and working backwards to what the goals for infants and parents should be. They determined the handicapped infant should become a person who is as independent as possible, have positive sense of self-worth, be accepted by others, maximize his or her capabilities, and be integrated socially into the family and community. From these long-term goals they developed several appropriate goals for families of atypical infants.

1. The family is able to integrate the disabled child into the family in a positive way having minimal impact on the physical, financial, and emotional status of the family, and the available time, energy and resources of the family are divided equitably among family members. Some of the important indicators they identified were: a) parents are aware of available resources that could help them in acquiring funds or services for their child's care and habitation; b) parents share in

TABLE II

INTERVENTION PROGRAMS FOR HIGH RISK AND HANDICAPPED CHILDREN (0-3 YEARS)

Model	Investigators and Program	Target Population	Major Program Goals	Parent Involvement Components
Home-based	Fraiberg, S. Intervention in infancy: a program for blind infants. Journal of Academy of Child Psychiatry, 1971, 10, 381-405.	Blind Infants	Human-object relations, adaptive hand behavior, gross motor development, body and self image.	Trained parents by intervention with babies in home. Primary goal is to help parents communicate with baby. Did not intervene with parent neurosis.
	Gordon, I. Reaching the child through parent education: the Florida approach. Paper presented at the American Education Research Association, National Convention, Feb. 1969.	Disadvantaged	Increase development of infant. Increase mother's competence and sense of self-worth; contribute to home life of infant.	Paraprofessionals visited mother in home. Curriculum structured to increase mother's competence and sense of self worth, and to contribute to home life of infant. Parent outcomes showed increase sense of control of mothers and improvement of quality of home environment.
	Karnes, Teska, Hodgins & Badger. Educational intervention at home by mothers of disadvantaged infants. Child Development, 1970, 41, 925-935.	Disadvantaged	Cognitive	Educational program for mothers. Increase maternal motivation.
	Kass, Gigman, Bromwich, & Parmelee. Educational intervention with high risk infants and young children. In T. Tjossem (Ed.) Intervention strategies for high risk infants and young children. Baltimore: University Park Press, 1976.	High risk and handicapped	Increase mother's sensitivity to child, improve infants skills, structure good environment, develop good working relationship with family.	Intervention based not only on needs of child but on assessment of mother/child interaction and environmental resources and limitations of the family and home. Intervention techniques with infants modeled and demonstrated for mother.
	Coyner, A., Local Utah Health Department Infant Development Program	Handicapped	Support Parents. Provide home/family management considering child & family's health & developmental needs.	Work with each parent to design individual program. Cluster groups of 3 - 4 parents for a specific learning experience.
	Levenstein, 1970, 1974; Madden, Levenstein & Levenstein, 1974. Verbal Interaction Project, Freeport, New York.	Disadvantaged	Cognitive, verbal interaction between mother and child.	Home visitors modeled verbal stimulation techniques which the mother then imitates. Home visitor encourages mother to read and play with child between home sessions to create learning opportunities. Exercises and games appropriate for infant are taught and fact sheets describing purpose and ways to carry out games are left in homes.

Table II (cont.)

Model	Investigators and Program	Target Population	Major Program Goals	Parent Involvement Components
	Ryan, T. J. Promoting Child Development Through a Program of Home Visiting Progress Report. Ottawa, Canada: Carleton University, 1972.	Disadvantaged	Sensorimotor and language.	Home visitors teach mothers how to provide sensorimotor experiences and language games for infants. Emphasis on ways in which parents can use daily interaction and caregiving situations.
	Shearer, D. E & Shearer, M. S. The Portage Project: A model for early childhood intervention. In T. Tjossem (Ed.) Intervention strategies for high risk infants and young children. Baltimore: University Park Press, 1976.	Handicapped	Gross and fine motor, social, cognitive, and language skills.	Parents taught how to keep records of behaviors learned. Parents taught what and how to teach: how to shape and reinforce behavior. Goals written for child.
	Bulletin of the High/Scope Foundation, 1974. Ypsilanti Carnegie Infant Education Program, Ypsilanti, Michigan.	Disadvantaged	Cognitive and language areas stressed.	Home visits expected to affect language, teaching, and management style of mothers.
Center	Badger, Ed. D. A mother's training program: a sequel article. Children Today, 1, no. 3 (1972): 7-11.	Disadvantaged	Cognitive Development	Mother's training program. Two hour weekly meetings with infant-toddler demonstrations, toy lending library, follow up home visits. Mothers learn to match toys to children's development.
	Bricker, W. A. & Bricker, D. D. The infant, toddler, and preschool research and intervention project. In In T. Tjossem (Ed.) Intervention strategies for high risk infants and young children. Baltimore: University Park Press, 1976, 545-572.	Equal # of handicapped nonhandicapped infants and toddlers.	Cognitive, language, and operant learning provided.	Parent education focused on language, motor, sensorimotor, social, and use of behavior modification. Complete assessment of family family needs upon entrance.
	Caldwell & Richmond, 1968; Braun & Caldwell, 1973. The Children's Center, Syracuse, New York.	Child Care	Social-emotional and achievement.	Parent education and social services provided for family. Day care but child attachment still occurred.
	Denhoff, E. & Hyman, D. Programs for developmental management. In T. Tjossem (Ed.) Intervention strategies for high risk infants and young children. Baltimore: University Park Press, 1976, 381-401.	Handicapped infants and toddlers	Individual education in major skill areas including social skills with adults and their children.	Discussion groups. Social worker available for specific help. Parent goals include understanding of child, awareness of child's growth, training in handeling, how to observe and interact with child.
	Hamilton (1972) Parent and Child Centers, Grandview & Crewport, Washington.	Disadvantaged	Physical, social, cognitive	Parent education and social services available. Home stimulation improved as a result of program.

Table II (cont.)

Model	Investigators and Program	Target Population	Major Program Goals	Parent Involvement Components
	Hayden, A. H. & Haring, N. G. Programs for Down's syndrome children at the University of Washington. In T. Tjossem (Ed.) Intervention strategies for high risk infants and young children. Baltimore: University Park Press, 1976.	Down's infants and toddlers	Motor, communication, social, cognitive, and self help.	Parent training to teach child.
	Haynes, U. B. The national collaborative infant project. In T. Tjossem (Ed.) Intervention strategies for high risk infants and young children. Baltimore: University Park Press, 1976, 506-534.	Handicapped	Total child and needs considered. Strengthen parent skills and understanding in care of training of child, minimize dependency upon outside intervention.	Focus on helping parents meet infants needs in a manner most congenial to development and attachment formation. Team approach developed to enhance parent-infant interaction. Staff sees parents as primary teachers.
	Heber, R. and Garber, H. The Milwaukee Project: a study of the use of family intervention to prevent cultural-familial mental retardation. In Friedlander, Sterritt, & Kirk (Eds.) Exceptional Infant v. 3 Assessment and Intervention. New York: Bruner/Mazel, 1975, 399-433.	Disadvantaged and low intelligence	Social-emotional, perceptual motor, cognitive, language. Rehabilitation for mothers.	Job training, home making, and child rearing skills for mothers.
	Mann, 1970. Tempe Arizona	Disadvantaged	Language	Mother-infant verbal interaction focus of program.
	Ramey, Collier, Sparling, Loda, Campbell, Ingram, Finkelstein. The Carolina Abecedarian Project: a longitudinal and multidisciplinary approach to the prevention of developmental retardation. In T. Tjossem (Ed.) Intervention strategies for high risk infants and young children. Baltimore: University Park Press, 1976, 629-665.	Disadvantaged	Language, motor, social, and cognitive development.	Social work services, nutritional supplements, medical care, transportation, payment for participation, parent-teacher training. Results show more mother-child interaction and better match between infant's vocal and mother's vocal in experimental vs. control groups.
Center/ Home Based Combination	Edgar, E. & Kelly, J. Development of model programs to serve handicapped infants 0-3 years and their families. Training Grant for 1979-1982.	Handicapped	Compare home and center based delivery models with regards to cost and ability to meet major goals: 1. Foster parent-infant interaction and attachment. 2. Promote infant growth in major skill areas. 3. Meet individual parent needs.	Parent needs assessment in all major areas. Assessment of parent-infant interaction. Goals and activities then designed to meet individual needs of parents. Parents and team members work and play with infants to enhance development.

Table II (cont.)

Model	Investigators and Program	Target Population	Major Program Goals	Parent Involvement Components
	Furuno, S. Enrichment Project for Handicapped Infants	Handicapped	Individual Programming, Cognition, Language, Gross motor, Fine motor, Social-emotional, Self-help, Parenting	Parent contact at least weekly. Parents involved in assessment and intervention planning. Program goals developed for individual parents. Saturday meeting for working parents. Mothers' and fathers' groups.
	Kentucky Rural Child Care Project: Child Care and Parent Involvement in Litchfield. Rural Child Newsletter, 1, no. 15 (1972).	Disadvantaged	Prenatal checks, child cognitive gains, parent education.	Until 3 months, home visitor comes to home to educate mother in all aspects of infant care. From 3 months to 2 years, child attends center with mother once a week for education activities. Mother continues to be involved. For parents: medical care, counseling, general instruction about concerns such as child development, nutrition, budgeting, and skill classes.
	Lally, J. R. & Honig, A. S. Education of infants and toddlers from low income and low-education backgrounds: Support for the families' role and identity. In B. Z. Friedlander, G. M. Sterritt, and G. E. Kirk (Eds.) Infant Assessment and Intervention. New York: Bruner/Mazel, 1975.	Disadvantaged	Prenatal nutrition, child development and child care information. Home visitors bring child development information to parents. Infant curriculum stresses cognitive, language, motor skills.	Parents receive home visits during prenatal period and after child is born until school age. Home visitor brings language, sensorimotor, child management ideas, information about community services, support, and friendship. Group discussion meetings available on request.
	Neilson, Collins, Meisel, Lowry, Engl, Johnson. An intervention program for atypical infants. In Friedlander, Sterritt, Kirk (Eds.) Exceptional infant vol. 3: Assessment and intervention. New York: Bruner/Mazel, 1975, 222-244.	Handicapped	Structured environment for sensorimotor experiences, language, motor, feeding, and pre speech.	Home visitors assess resources and emotional status of parents. Focus, however, is on child. Activities and intervention strategies taught to parents. Discussion group available. At 12-18 months infant age, preschool program with parent observation.
	Rynders, J. E. & Horrobin, J. M. Project EDGE: The University of Minnesota's communication stimulation program for Down's syndrome infants. In Friedlander, Sterritt, Kirk (Eds.) Exceptional infant vol. 3: Assessment and intervention. New York: Bruner/Mazel, 1975, 173-192.	Down's Syndrome	Maternal tutoring focused on communication devlopment.	Intense 6 week training program in homes and at University in which parents learn to use instructional methods. Then, home visits semi-weekly and group meetings. Parents are trained to provide one hour of tutoring to child. Preschool at 30 months for child.

decision-making about the child; c) parents are able to maintain good physical and emotional health; and d) parents maintain their outside interests and social activities. Other indicators could be that parents have strategies for setting priorities and responding to individual needs of family members, and that the spouse and siblings report that they do not feel ignored.

2. Parents deal constructively with their strong feelings about the disabled child. Some of the important indicators they gave were: a) parents constructively deal with their feelings so that they show realistic expectations about their child's future development and performance; b) the parents are able to list the probable accomplishments they could expect of their child over the next 6 months. c) Another indicator could be that the parents spontaneously report their child's positive attributes.

3. Parents acknowledge and deal with the feelings and questions of the siblings, and with the intrusions on the family by others. It is important that parents understand the child's diagnosis when it is known, and have the knowledge to explain it to others. When faced by advice from others, they should be able to judge the value of the advice, and ignore it if it is invalid, follow it if it is valid, or seek more information if they cannot judge its validity.

4. Parents feel competent as the parents of the disabled child. Indicators of this might be that the parents accurately access the child's developmental level or needs, and discriminate between behavior problems due to the child's disability and problems invalidated to the disability. Do parents feel they can provide for the child's physical needs, and provide a growth fostering environment in terms of social emotional behavior?

One of the paradigms we have developed to look at parent-child interaction is to examine the characteristics of the caregiver and the child in an interaction (Barnard, 1979). The caregiver should be sensitive to the cues of the child, should alleviate the distress of the child, and provide a social/emotional and cognitive growth fostering environment. The child feeds into the interaction by presenting clear cues, and by being responsive to the caregiver. Infant programs can promote the positive development of this caregiver-child interaction by increasing the caregiver's sensitivity to the child's cues, and by helping them to expect realistic goals for their child. Parents need to learn to recognize what kind of distress should be alleviated, and what kind of behavior should be ignored. This is related to knowing how to provide a cognitive and social emotional growth fostering environment for the child. In the face of unclear cues, or lack of responsiveness from the infant, how can parents be helped to sustain their efforts with their child? Kelly (1979) found that there was a high rate of parental controlling behavior in responding to the handicapped infant. From what we know about research in normal children, this controlling behavior, or restrictiveness and intrusiveness, is a limiting activity of the caregiver and inhibits the child's eventual development.

One basic overriding goal that should be a part of all parent-infant programs is to increase the parents' feelings of self-worth and competency in dealing with their child. The research we have cited points out that sustained long-term results will not occur unless the parents are given advice and support to increase their involvement and responsiveness.

B. Assessment of Parent Needs

An effective parent involvement program assesses each family on an individual basis. Areas of concern that need to be assessed are: the family's available resources for coping with the effects of having a handicapped child, and the need for more information about specific handicapping conditions, diagnostic procedures, available treatment services for the infant and family, and available groups, organizations, and community services. These areas can be addressed during a formal or informal interview with the parents. The following list of questions can be used to assess the available resources of the parents. The need for information in the additional areas listed above can be recorded on a checklist.

PARENT

Parent Available Resources Evident and Timely

1. Does the mother easily express her feelings about the disabled child?
2. Does the father easily express his feelings about the disabled child?
3. Do the parents have open communication with each other?
4. Are the parents satisfied with their relationship with each other?
5. Do the parents express positive affect to the child?
6. Do the parents have good health?
7. Do the parents report few life changes?
8. Do the parents report support from family or friends?
9. Do the parents have accurate knowledge about the child's condition?
10. Do the parents have realistic developmental expectations for the child?
11. Were the parents involved in seeking this resource?
12. Are the parents interested in learning how to best care for their child?
13. Do the parents have a child who responds positively to them?
14. Do the parents have hope that their child will improve?
15. Do the parents have a regular source of personal health care?
16. Do the parents have adequate financial resources to meet their needs?
17. Do the parents know how to get the information they need?
18. Do the parents demonstrate high self-esteem?
19. Do the parents each have 13 or more years of formal schooling?
20. Do the parents support activities outside the home that they enjoy participating in?

If the program goals include facilitation of parent-infant interaction, which the review of literature has shown is a primary influence on early development, then observational methods are a necessary part of a parent needs assessment. Two instruments developed to assess the quality of parent-infant interaction are the Parent Behavior Progression developed for the UCLA Infant Studies Project (Bromwich, 1976), and the previously mentioned Nursing Child Assessment

Project's Teaching and Feeding Scales developed at the University of Washington (Barnard, 1979). The Infant Program at the Child Development and Mental Retardation Center, University of Washington (Kelly, 1980) in coordination with the Nursing Child Assessment Project, is currently using the latter instrument to assess parent-infant interaction. Meisel (1977) reviewed several other scales designed to assess parent attitudes and behaviors.

C. Intervention Activities

After assessing individual parent needs through interviews and observational methods, the identified areas of concern must be prioritized, and activities to address the more significant needs must be developed and implemented. Continued assessments of parent concerns and parent-infant interaction should be conducted at specified times. Parents should be informed of all assessments, and assessment information should be kept in the infant's permanent file. The following hypothetical case illustrates these procedures.

> Sheila and Tom, concerned parents, referred by a local pediatrician, and Janice an eleven-month-old infant contacted an infant program serving handicapped infants and their families. The parents were in the process of adopting Janice, who had been in their care for four months. Janice's pediatrician had recently evaluated her and determined that Janice's development was not progressing normally. After further diagnostic procedures, and probing by the parents, the pediatrician suggested that Janice might eventually be diagnosed as having cerebral palsy. The pediatrician also suggested that the delay could be a result of Janice's earlier deprived environment, and that her eventual potential with an enriched environment was very difficult to predict.
>
> The parents easily expressed their concerns about the possible diagnosis. They had two primary concerns. First, how could they decide whether or not to adopt Janice, given the inconclusive results of the evaluations and their own lack of knowledge of what personal and family adjustments are necessary if a child does have cerebral palsy or another handicap. Secondly, although they loved Janice and were presently committed to helping her develop in whatever way they could, neither of them were prepared to provide a specially structured environment that they felt would be necessary for raising a handicapped child. Sheila had read that a child learns various skills at its own natural rate, and that it is not effective to attempt to teach a skill to a child before it is ready. With this in mind, how could she and Tom or the infant program staff accelerate Janice's development? During the next month of visits there was a scheduled observation of Janice and Sheila, the primary caregiver, during a teaching and feeding situation. During teaching the mother was sensitive, responsive, and emotionally involved with her child. Even though her motor movements were somewhat disorganized, Janice's cues were clear, and she responded to her mother with obvious affection. During feeding, some tension was observed in both the mother and the child. After the observation the mother explained

that recently she had not enjoyed mealtime as much because Janice's appetite had waned. Even though Janice was thriving now, she had been seriously ill at the beginning of placement, and Shiela was concerned for her health.

The parents had good health, adequate financial resources, and good health care. They had recently moved to the area, and did not have family or close friends close by. They both felt fortunate that their own relationship was a source of strength throughout this crisis.

With this information, the parents and infant staff designed the following beginning activities. To help with their concern about the effect of adopting a handicapped child, Sheila and Tom decided to join a supportive group of parents of handicapped infants and toddlers with whom they could discuss their feelings. A counselor who was a member of the infant team was also available to meet with them upon request. Sheila and Tom felt that these two resources, in addition to the adoption agency, would help them make their decision about adopting Janice. In addition, a thorough evaluation with neurological testing was scheduled for Janice. Diagnostic information, although still inconclusive, was thoroughly explained to the parents.

The parents were also concerned about their ability to foster Janice's development. Over the past month Sheila had been involved in a detailed assessment of Janice's skills, and she felt she understood what Janice could do. Sheila and the staff worked together to structure a home environment that encouraged Janice's social, motor, and cognitive development. As Janice accomplished new skills, the environment was altered to facilitate continued growth. It was never suggested that the relationship between Sheila and Janice should be altered. For the most part, Sheila still presented the activities. The great importance of play never was undermined. Whenever possible, reinforcement of specific aspects of Sheila's interaction style and Janice's responsiveness was given.

A nutritionist examined a record of Janice's food intake and discussed the baby's eating patterns. A follow-up assessment of the feeding situation by the mother and case manager was scheduled soon after.

The information recorded during the interview assessing parental resources and concerns was updated quarterly. The teaching and feeding observations were rescheduled in two quarters. The mother was always aware that this assessment information was being gathered. The information was kept in Janice's permanent file. Although the father could not be at these sessions, Sheila conveyed all she could to him.

This case description was included to illustrate the procedures involved in assessing and prioritizing concerns and developing and implementing intervention

activities. The description of these procedures did not attempt to convey the parents' feelings of sorrow and frustration or the staff's occasional feelings of helplessness. Many parent-child interactions are seriously at risk; many children lack the capability to offer clear cues; and many parents do not enter a program trying to decide whether or not to keep their child. This situation was presented as one unique illustration. The indecision to keep Janice or not (expressive concern) and the need for information about diagnosis and treatment (technical concern) were both recognized and dealt with by the parents and staff.

The parents in this case had a high level of available resources. Even with these resources, however, the supportive services of an intervention program were badly needed. As mentioned in the review, Dunlap (1979) found that even when the family had adjusted well, and there had not been a significant effect on the family life, there was still a great need for supportive services that could ease some of the demands created by a handicapped person. Intervention efforts, therefore, must be designed to assess the needs of such families and find adequate ways to provide services.

D. Parent Involvement in Planning, Decision Making, Evaluation and Dissemination

In addition to developing activities that respond to parental concerns, infant programs also need to involve parents in planning, decision making, evaluation, and dissemination activities. Wiegerink, Posante-Oro, and Bristol (1978) reported on a survey of how nine programs for handicapped preschool children involved parents in their programs. Two of the categories for parent involvement were: (1) "Parent assistance in planning, developing, operating, and evaluating project," and (2) "Opportunity for parents to advise and assist in information dissemination concerning the project." The nine programs reported involving parents in the following ways: (a) employment as paid staff members; (b) assistance in raising funds; (c) decision making in allocating budget; (d) decision making in program evaluation; (e) decision making in setting program goals; (f) instructing/training other parents; and (g) participating in public relations for the project. (Wiegerink and Hocutt (1980) have recently completed a survey of the parent involvement efforts of 34 HCEEP projects.)

One way to involve parents in many of these activities is to establish a parent advisory council for the infant program. The council could work with the program to involve as many parents as possible in some or all of the previously mentioned activities. The council could also help develop and conduct a parent satisfaction survey that could provide important information for making program changes.

This section of the paper discussed four related factors relevant to parent involvement in infant intervention. These factors may be supplemented or altered as program developers incorporate new experiences and research ideas into their programs.

III. SUGGESTIONS FOR FUTURE RESEARCH ON INFANT INTERVENTION: PARENTAL CONSIDERATIONS

There are several unresolved issues in infant intervention that could affect parent participation and that need to be researched systematically. The following

three research topics are examples of projects that could influence effective change.

A. The effectiveness of different service-delivery models needs to be evaluated and compared with respect to the individual characteristics of the infant (e.g. the infant's chronological and developmental age and handicapping condition) and the parents (e.g. their educational level, available support system and caregiving experience).

The relative advantages of different program models is a subject of debate with very little empirical evidence to support the choice of one type of program over another. In order to study this issue, researchers must examine the available literature on infant and parent needs, and develop research questions based on this literature. Let us review, for example, several studies that could be used in developing good research questions for studying service to the 18-36 month old population.

Literature is accumulating that casts serious doubt on the efficacy of separating handicapped toddlers from their mothers for long school days. There is some evidence that handicapped children display less attachment behavior (Prechtl, 1963; Stone and Chesney, 1978; Stone, 1979). If handicapped children do become attached, they are likely to experience difficulty advancing through the separation stage and separating a child before the child has separated himself can have harmful effects (Mordock, 1979).

Bricker and Carlson (1980) recently reported the results of a language study with Down's Syndrome infants. They found, among other things, that the prelinguistic social-communicative developmental trends of infants with Down's Syndrome resembled, but were behind, those observed in non-delayed children. In non-delayed children the emergence of coordinated actions -- that is, the ability to use objects to attract adult attention and use adults to retrieve desired objects -- occurs between 11 and 13 months of infant age (Sugarman, 1978). Bricker and Carlson found that this also occurred in the delayed children, but at a later chronological age.

Another phenomenon that occurs in non-delayed children in the latter half of the first year -- resulting from the increased development of affective and sensori-motor abilities -- is the infant's strong attachment to its primary caregiver (Stern, 1974). Perhaps attachment behavior in some handicapped children is delayed at the same rate that Bricker and Carlson found social-communicative skills are delayed. If so, the caregiver's presence and involvement in the preschool setting could be critical for the eventual delayed attachment and interaction between parents and handicapped infants.

Research efforts need to address these types of questions so that appropriate models of service delivery are developed for handicapped infants and their families.

B. The efficacy of integrating birth-to-three handicapped and non-handicapped infants needs to be examined.

The Developmental Disability Contract for King County Infant Intervention Programs in the state of Washington required all funded programs to submit in writing, by the beginning of May 1980, a plan for providing an integrated preschool program. An integrated program is defined as "a structured learning program involving disabled and nondisabled children utilizing the maximum extent possible the services and facilities of the generic service provider." (King County DD Contract, Exhibit A, January, 1980). This requirement is probably in response to the emphasis on mainstreaming and the provision of a least restrictive environment mandated by Public Law 94-142. The effects of integration on parent-infant attachment and interaction, parent adjustment to having a handicapped child, and parent participation need to be examined. Again the individual characteristics of both the infant and the parent need to be considered in the research.

C. The development, implementation, and effectiveness of methods for involving parents working outside the home needs to be studied.

The involvement of parents working outside the home remains a serious dilemma with no ready solution. The important contributions of the father have been recognized in recent years (e.g. Brazelton, 1979; Clarke-Stewart, 1978; Lamb, 1977; Howells, 1973). Methods for involving both mothers and fathers in the intervention process need to be developed and the May 19, 1980 issue of Newsweek reported that 43% of mothers with children under six years of age were working outside the home. These facts emphasize the need to develop, implement, and evaluate methods for involving both working mothers and fathers in the intervention process.

CONCLUSION

The literature on infants and infant intervention demonstrates the importance of parent participation in programs for high risk or handicapped infants. Infant programs have responded by including parents in intervention programs in a variety of ways.

The type and extent of parent involvement depends on the appropriateness of the program's goals, assessment procedures, and intervention activities. Further guidelines need to be developed for concentrating on parent needs in intervention efforts.

In order to make effective decisions about program goals, model of service delivery, and staff role descriptions, program developers must have adequate descriptive and empirical knowledge. There is a need for researchers to study the effects of program elements on parent and family adjustment to having a handicapped child, parent-infant interaction, and the long-range adjustment of the child in society.

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IV. COMTEMPORARY THEORY
Alfred Healy, M.D.

These guidelines apply to early intervention services for infants who fall into the following classifications:

1) Infants with discernible handicaps at the time of birth;

2) Infants who have conditions or diseases that, when recognized at birth by biochemical or other means, can lead to prevention of handicapping conditions later in life;

3) Infants whose births are associated with maternal (social or biologic) factors or infant (biologic) factors that place them at high risk for the eventual development of a handicapping condition; and

4) Infants who exhibit a delayed or otherwise abnormal development course whose births are not associated with social or biologic factors that place them at high risk for developing handicapping conditions.

These guidelines do not apply to the large number of infants who are at risk for underachievement in life skills solely because of social or environmental reasons, and who could profit from infant/caregiver intervention prior to the onset of an abnormal developmental course. These guidelines do apply to the many low-birth-weight and otherwise distressed infants who have been discharged from neonatal intensive or intermediate care nurseries. The complexities of the care and support required by the infants, their parents, nursing, medical, and other support personnel as they cope with the stress of daily life and death concerns of the infants when they are confined to the nursery setting are beyond the scope of these guidelines. Special interventions are required to provide appropriate care for the infant and support to the parent and medical/nursing personnel, and are subjects of current investigations.

CONTEMPORARY DEVELOPMENTAL THEORY

It is now recognized that the development of children is influenced in part by ongoing transactions between a child and his/her caregivers. It is no longer tenable to view the child as a plastic, moldable substance totally dependent upon environmental influences, nor to assume that the infant's eventual outcome is totally dependent upon his/her genetic endowment regarding motoric, cognitive, and adaptive skills. Thus, an infant's developmental course is influenced by both genetic and environmental variables. Many intervention curricular models developed during earlier times, emphasized specific developmental areas related to the child (cognitive, motor, language, self-help). More recently, the affective components and the related child/caregiver relationships have been recognized as very important aspects when planning programs for a developmentally disabled child. The handcapping condition may introduce other variables that increase the complexity of child/caregiver interactions. Based on the findings of longitudinal studies, the dyad interactive style during the first few months and subsequent early years has a long-term affect on the child's development and relationship with his/her caregiver, other adults and peers. There is, therefore, ample justification for the early identification and removal of barriers that may interfere with positive outcomes of these child/caregiver interactions.

Barriers to successful infant developmental outcomes include factors that directly and immediately impact on the interaction between parent and child, or factors that may indicate that such relationships are at risk for optimal outcome. Such risk factors include social and biologic items that indicate a higher than usual chance that a child will eventually experience difficulty in achieving life skills. Social factors may include availability, knowledge and use of prenatal health care services, teenage mothers, and parent's educational status. Maternal biologic factors include diabetes, hypertension, abruptio placentae, premature delivery, and others. Infant biologic factors include low birth weight, perinatal anoxia, neonatal sepsis, intrauterine growth disturbance, congenital infections, and others.

Not all infants who eventually develop handicapping conditions are associated with maternal and infant risk factors. The specific reasons why this occurs are not fully understood. Lack of appreciation for the potential serious consequences of factors such as mild perinatal asphyxia and mild hyperbilirubinemia may be influential. In addition, increasing evidence suggests many risk factors are intertwined with supportive care provided infants following birth. Conditions such as retrolental fibroplasia, bronchopulmonary dysplasia and necrotizing enterocolitis are under intensive investigation at the present time.

In summary, contemporary developmental theory favors the following clinical assumptions:

- Contemporary child development theories provide the foundation upon which the rationale for effective identification, assessment and intervention programs are based.

- Handicapping conditions often interfere with optimal development and must be identified as soon as practical to eliminate or reduce their impact on both child and family development.

- Certain diseases or conditions are immediately discernible at birth or are associated with practical detection methods, and such infants are commonly recognized as in need of immediate intervention strategies.

- Certain social or biologic factors have been identified in high correlation with children who eventually demonstrate handicapping conditions; these factors can be useful in structuring periodic developmental assessments of such children.

- Certain children who eventually develop handicapping conditions are products of "non-risk" pregnancies and deliveries; therefore, access to an availability of developmental assessment programs for all infants and young children is optimal.

CLINICAL CONTINUUM OF DISABILITY RECOGNITION

There is a need to organize a continuum of professional and agency services to assure that those with discernible conditions at birth are immediately recognized and cared for, that all newborns are screened for

conditions which are preventable or can be ameliorated, and that those with risk factors are adequately and periodically screened and evaluated if necessary. In addition, every infant and young child, irrespective of their risk status, must have available adequate services to detect delayed or otherwise abnormal development, and parents must be informed of their child's current developmental status and projected outcome.

This continuum of recognition extends from birth through approximately three years of age. Organized screening projects (infant high risk follow-up programs, newborn metabolic screening programs) are often agency organized, funded and implemented. Projects to systematically screen general populations of children (EPSDT, school-based preschool screening projects) use a mixture of agency personnel and professionals from the private sector of health care.

At birth, the majority of discernible problems are sensory related (cataracts), motoric (hypotonia, paralysis), anatomic (clefts, meningomyelocele) or chromosomal abnormalities (Trisomy 21). Very few infants are labeled as experiencing central processing difficulties at birth (mental retardation, language or communication disorders) as these are behaviors not yet developmentally manifest, although the condition may be ultimately associated with such a deficiency (Trisomy 18 and mental retardation). Newer techniques utilizing computer summed auditory and visually evoked responses have allowed central processing functions to be monitored, but they do not assess developmental behaviors. The passage of two to three months is required before delays in these behaviors reflecting deficient central processing can be detected. However, as the infant increases in age, fewer new sensory and motor deficits are detected and an increasing number of central processing difficulties become evident. The more severe the degree of retardation, the younger the infants/children will be when they manifest behaviors suggestive of this disorder. Similarly, learning disabilities are infrequently discerned prior to the introduction of academic material in the school years.

During the first three years of life, there is an increased likelihood that each of these handicapping conditions will be associated with health or functional disorders that require care and intervention provided by health professionals. Growth disorders, feeding problems, frequent and severe respiratory infections, seizures, constipation, urinary disorders, and skin conditions are all frequently associated with major disabling conditions. The more severe the handicapping condition, the more likely there will be an associated health and/or functional disorder.

CONTINUUM OF NEONATAL CARE

A system of care for normal and high risk pregnancies, coupled with neonatal care units for infants, has evolved in this country around a primary, secondary, and tertiary care focus. Pregnancies identified as being at low risk (70%) are cared for in primary or community-based facilities. Those pregnancies associated with a higher risk of fetal or maternal diseases are treated in or transported to secondary centers (20%). Infants or their mothers judged to have discernible diseases or conditions requiring a level of care not available at primary or secondary levels are transferred to tertiary level

centers where any level care is available (10%). At the time of discharge from all levels of neonatal care, adequate plans must be established to ensure routine infant care as well as special care programs designed to meet the metabolic, respiratory, or neuromuscular, etc., needs of the infant. At this time, the follow-up plan to periodically assess the developmental progress of the child must be established. The use of community-based agencies and private health practitioners all should be incorporated in a cost effective manner.

At each level of neonatal care, whether primary, uncomplicated care, secondary, or tertiary neonatal intensive care, there is the opportunity to:

- Recognize and record all significant current and historical social and biologic risk factors in the family.
- Intervene when possible to prevent or ameliorate risk factors.
- Recognize and record all significant potential and actual infant biologic risk factors.
- Recognize and record all discernible diseases and conditions present in the newborn.
- Organize and implement a process to detect all infants with metabolic conditions whose effect may be prevented or ameliorated.
- Communicate all of the above information to health care professionals providing ongoing health supervision or direct medical care to the infant.
- Communicate all of the previous information to regional or statewide follow-up programs who systematically screen high-risk infants for developmental disorders.
- Communicate appropriate information to an early intervention program. (Chapter VI).

IMMEDIATE POSTNATAL CARE PROGRAMS

Certain conditions and problems are readily discernible at birth and require intervention even before the emergence of developmental behaviors judged to be suspect or abnormal. These conditions include:

- Blindness or significant visual disorders.
- Deafness or significant auditory disorders.
- Major craniocerebral malformations (microcephaly, hydrancephaly, hydrocephaly).
- Structural musculoskeletal, or neuromuscular deformities (spina bifida, arthrogyposis, congenital amputations, limb paralysis).

- Chromosomal disorders and major malformation syndromes (Trisomy 21, 13, 18 or other multiple malformations).
- Health impairments (cystic fibrosis, infantile seizures, congenital heart disease).

Early intervention programs can provide the following services to such infants:

- Ongoing health care supervision.
- Ongoing medical care of the disabling condition or health concern.
- Parental support and guidance to understand, accept and handle the child's abilities and disabilities.
- Recognition of potential or actual child/caregiver interactional difficulties that could interfere with optimal child and/or family development.
- Regular and periodic evaluation of the child's developmental progress and implementation of intervention strategies if judged to be appropriate.

FOLLOW-UP AND SCREENING PROJECTS

Infants who do not have discernible handicapping conditions at birth, but are identified as being associated with maternal or infant risk factors, require periodic and systematic evaluation of developmental progress. If the developmental behaviors of infants and young children were periodically and systematically assessed, special screening projects devoted to categorical high-risk subpopulations would not be necessary. However, those factors which place a child at risk for developmental disabilities are often similar to the factors interfering with the child's ability to participate in screening projects and to regularly utilize health services. Because only 50% of children at 36 months of age are regularly seen by health practitioners, there remains a vital need to continue screening projects at the present time.

An infant or child should be referred to definitive evaluation units for specific reasons. Diagnostic evaluations, advice concerning health care practices, emotional support to over-anxious parents, all may be valid reasons singly or in combination. The most important factor to remember is to use screening instruments for the specific purpose of screening developmental progress, and not to distort their intended use into diagnostic instruments.

Every child born without associated risk factors who is receiving ongoing health care supervision requires periodic developmental screening. Each health care professional must be capable of providing definitive developmental assessments or to refer infants and children to facilities or persons who can provide such definitive evaluations. Again, failure to pass items on a screening assessment indicates the need to refer to a center where definitive assessment can be carried out by appropriate professionals. The assessment of the infant's or child's neurobehavior must be as paramount as the accomplishment of specific developmental tasks during this type of diagnostic effort.

The process of defining handicaps has changed over the past decade. In addition to categorical anatomic and physiologic diagnostic systems, descriptions of functional abilities and disabilities have been increasingly utilized. This movement has greatly assisted the delineation of the specific services required by a child. Physicians, nurses, early childhood educators, and administrators must coordinate their professional disciplines while at the same time relate to federal and state laws that dictate differing orientations to the same child.

For example, an infant deficit in the enzyme that metabolizes phenylalanine has a medical diagnosis of phenylketonuria, but this term may have little meaning for a preschool educator. If a diet low in phenylalanine is not followed, the accumulation of an excess amount of phenylalanine and its metabolites causes brain damage, resulting in severe mental retardation, often accompanied by seizures. However, as infants, the term mental retardation is inappropriate and often a somewhat nebulous description such as "developmental delay" is used. Therefore, the same child could be labeled phenylketonuric, mentally retarded, or developmentally delayed, yet the child has a genetic birth defect that requires monitoring and intervention to prevent a permanent mental disability.

When a functional behavioral model is utilized in an interdisciplinary sense, professionals can readily understand the impact of each component of this developmental model upon the observable behaviors that each discipline eventually observes and assesses. All disciplines must observe and be knowledgeable about all behaviors so they may judge the impact of what they consider important to their discipline. By tradition, professional training and agreement, however, each component is formally evaluated by specific disciplines (e.g., hearing by audiologists) even though all professionals have a vital interest in whether the child can adequately hear. This functional approach to the developmental assessment allows an infant without a specific medical diagnosis to be enrolled in an early intervention program and to receive appropriate services.

SUMMARY

Infants requiring early intervention programs can either be identified at the time when the condition becomes obvious, or when systematic screening indicates they are at high risk to develop disabling conditions. Both processes allow a comprehensive approach to the infant's needs and provide a method whereby the infant not only can be enrolled at the appropriate time but also will be enrolled for the proper reason.

1) Infants with obvious defects observable at birth require immediate association with early intervention programs to:

   . Assist parents in coping and accepting the handicapped child.

   . Provide needed information regarding medical and health concerns.

   . Provide information regarding feeding, elimination, positioning, and handling.

   . Assist in securing competent assistance as new problems become evident.

2) Infants who are detected in the newborn period to have biochemical or other associated medical conditions that, unless corrected early in the child's life, will lead to handicapping conditions require:

   . Parental education and emotional support

   . Periodic medical/health care and developmental assessment

   . Special diets and/or medications

3) Infants whose births are associated with known familial or infant high-risk factors require referral to:

   . Physicians or agencies that will periodically and systematically screen the developmental progress of the infant

   . Agencies or programs utilizing an interdisciplinary approach which will competently evaluate development if a screening test indicates potential developmental delay

   . Early intervention programs that will provide infant care and parental support while medical and/or cognitive diagnostic testing is accomplished over an extended period of time

4) Infants whose birth was not associated with risk factors, and therefore, those parents and medical/health supervisors are unsuspecting of the potential development of handicapping conditions require:

   . Periodic and systematic health care supervision that monitors the infant's developmental progress

   . Immediate and appropriate referral to appropriate evaluation units if suspected of developmental problems

   . Continuous coordination of all needed services including health and/or medical care

V. RECOMMENDED GUIDELINES FOR EARLY INTERVENTION PROGRAMS

The primary purpose of early intervention programs is to optimize the health and development of the handicapped infant and his family. Regardless of the sponsoring agency there are certain fundamental guidelines which should be observed if the program is to achieve the desired outcome. Guidelines should be consistent with the standards developed in the state plan for early intervention programs for handicapped infants. (Chapter VI)

It was the consensus of the participants in the Conference that the success of any measures for normalizing the infant's development must begin with consideration of and focus on the infant-family unit. It was also agreed that physical health needs of the at-risk handicapped infant must be addressed before optimal psychosocial and other developmental progress can be achieved. For this reason, these guidelines recommend assessments and interventions which address infant/family physical health needs, infant/family psychosocial needs, and other developmental needs of the infant in that order. The focus, however, must be on meeting the total needs of the child and on the importance of bonding and attachment for infant-caregiver relationships. The recommendations are intended to exemplify and reflect the current state of the art knowledge of infant and family development that has been identified by contemporary developmental theory and in the application of recent research findings by Conference participants.

PROTECTING PHYSICAL HEALTH

Entry into early intervention programs should be initiated by referral from a health care provider or health care system which documents the reason for referral (i.e. presence of a disabling/handicapping condition) and the need for early intervention services/(e.g. difficulty in feeding).

Assessment

1. Identification of a disabling/handicapping condition should be established by use of infant and family health histories, by complete physical examination, and observations of functional abilities.

2. Comprehensive evaluations may utilize multiple diagnostic services available in a single health care agency (Crippled Children's Services (CCS), University Affiliated Facilities (UAF), Rehabilitation Center, or other similar services, or multiple private diagnosticians (physicians, audiologists, physical, speech and occupational therapists, psychologists, community health and/or pediatric nurses, nutritionists, social workers, etc.)

3. The health care provider/system has primary responsibility for a comprehensive evaluation and reports to other providers and programs should include evidence of the following:

   - Complete physical examination and systems review

   - Perceptual screening (visual and auditory)

- Laboratory examination as indicated, including cytogenetic and biochemical genetic studies

- Nutritional assessment and status, including diet and feeding practices

- Anthropometric measurements

- Family history and pedigree

- Sensory-motor (neuro-developmental) evaluations

- Patterns of physiologic rhythms, including sleep-wake, feeding, and alertness-response patterns, etc.

- Oral health assessment

4. Comprehensive evaluations should be accomplished by an interdisciplinary team.

5. Cooperative agreements should be established between health care providers and early intervention programs to facilitate initial diagnostic evaluations, referrals, and periodic re-evaluations.

6. The home should be assessed for safety provisions and the adequacy of the physical environment for the infant and his family.

7. Family members and other caregivers should be assessed for current health status and the identification of factors which could influence the home environment and the infant's health.

8. The parents' perception of the infant's disabling/handicapping condition, the treatment program and prognosis should be assessed (initially and reassessed) at regular intervals.

Intervention

1. Any plans for interventions related to health care should include measures to insure that parents receive a thorough explanation of the etiology and nature of the problem, the recommended remediation measures, possible complications, and desired outcomes of interventions.

2. Initial interventions should stabilize the infant's primary health processes and address measures to insure physiological stability and integrity.

3. A primary health care provider should be identified and assume responsibility for: (1) well baby/child (preventive) care according to the schedule recommended by the American Academy of Pediatrics, (2) early identification and treatment of acute and chronic health problems, (3) ongoing reassessment of total health status, (4) liaison between

all health care providers and any other early intervention services, and (5) communication with families.

4. Ongoing health interventions should be designed to maintain the infant's optimal health status, including maintenance of adequate respiration, nutrition, elimination, motor processes, and other measures needed to support surgical, medical or other therapeutic interventions.

5. Habilitative interventions, which may include physical, occupational, or speech therapy as well as the use of prosthetic or orthotic appliances, should be provided as indicated. These interventions should be developmentally appropriate and planned in conjunction with medical specialists and coordinated with parents and early intervention staff.

Evaluation

Evaluation of preventive, maintenance, restorative, and curative health services should be carried out by the primary health provider and the parents on a regular basis. The individual infant's optimum health status will be unique and will vary depending on the interplay of multiple complex factors (i.e. the handicapping condition's response to health care measures, family factors, access to needed health, therapy and/or social and education services, etc.) In order for intervention processes and outcomes to be measured for program (and/or client) effectiveness, it is imperative that evaluation measures be determined prior to the intervention, and that such measures be regularly documented and consistent with current professional practice. The number of parameters to be considered should also be predetermined, although flexibility should be allowed for additional parameters as the need evolves.

PROMOTING OPTIMAL PSYCHOSOCIAL DEVELOPMENT

The physical and psychosocial health status of infants is directly correlated to the psychosocial wellbeing of the family; therefore, services that facilitate growth-fostering interactions between the infant and his primary caregiver and other family members are recommended.

Assessment

1. Assessments of the psychosocial status of the infant and his family should be supported by observations in the home at the time of referral and at regular intervals. (Every three to six months during the first two years.)

2. The following factors should be considered in assessing the family:

   - Demographic data, including education and income levels

   - Stresses within the family, including significant life changes, financial resources, family strengths, the availability and use of support systems, value systems, and cultural influences.

3. The ability of parents to nurture the infant should be assessed at regular intervals. Needed assessment data would include the following:

   - The style and patterns of parenting
   - Knowledge of infant development, infant care needs, and the infant's handicapping condition
   - The repertoire of nurturing behaviors of each family member

4. The infant's behavioral patterns should be assessed at regular intervals to determine the following:

   - Attachment to a significant person and evolvement through stages of the separation/individuation
   - Ability to modulate and control states of alertness and response patterns
   - Patterns of physiologic rhythms
   - Length and frequency of sustained attention
   - Repertoire of goal-directed behaviors
   - Perceptual discrimination and integration
   - Intrinsic motivation
   - Style of temperament
   - Description of the infant's typical day-established routines, allowance for autonomy vs. control, use of toys, playtimes, and where he spends his time

Intervention

1. Interventions should be family centered from birth until two years. These are often home-based, but may be obtained in a center provided strong parental involvement is emphasized. The setting should be determined by family choice and/or need.

2. If a transition or modified group/preschool program is available, the infant might enter such programs between 24 and 36 months of age, depending on his developmental readiness for physical separation from home and family.

3. Parents should be the primary interveners. A case (or client) manager will help the family adapt special therapy and care needs as well as developmental approaches into the daily home routine.

4. Parents should participate equally with a case manager and other program staff in planning, implementing, and evaluating assessment and intervention strategies.

5. Parents should be allowed to choose their level of participation in a program; for example, they could choose to not participate in parent groups or therapy, etc.

6. Unusual and temporary or long-term circumstances or other family changes should be considered in developing infant and parent interventions.

7. Referrals or other interventions based on needs for additional family/infant services should be instituted as necessary; needs for financial support, food supplement programs, respite care, family counseling, EPSDT or other health services, genetic counseling, etc.

8. Interventions should strengthen parenting skills by increasing a positive self-image, establishing a supportive environment, and promoting parent mutuality.

9. Interventions should help foster attachment between the infant and a significant person.

10. Interventions should be developed which increase the caregiver's sensitivity to the infant's cues and help in planning realistic goals for the infant.

11. Interventions should be designed to increase the infant's responsiveness to his animate and inanimate environments. Learning by doing should be stressed rather than learning by "being done to."

12. Strategies for parental training should be clearly delineated from strategies designed to provide emotional support and/or counseling.

Evaluation

1. Evaluation of early intervention services to families should measure the following outcomes:

   - The family is receiving and utilizing needed health, social and education services.

   - The family utilizes appropriate support systems.

   - The family deals constructively with strong feelings and crisis situations.

   - The handicapped infant is integrated into the family with minimal impact on the physical, financial, and emotional status of the family and its individual members.

2. Evaluation of early intervention services to handicapped infants should measure the following outcomes:

   - The infant achieves optimum physical and psychological independence.

   - The infant evidences movement along the separation/individuation continuum.

   - The infant demonstrates a positive sense of self-worth.

   - The infant is accepted by others.

FACILITATING MOTOR, COGNITIVE AND COMMUNICATIVE DEVELOPMENT AND SELF CARE SKILLS

When the infant's physical condition has been stabilized and his physical and psychosocial needs have been addressed, early intervention programs should offer additional services. Consultations and/or direct services from teachers, psychologists and/or therapists can help the parents and case manager integrate developmental therapies and approaches into the infant's daily home routine.

Assessment

1. Assessments of developmental function should be carried out in the home and may be supplemented by special testings or evaluations in clinics, offices, or other community facilities.

2. Standardized developmental assessment tools/tests should be used, using the paradigm of each infant serving as his own control.

3. Assessments of the infant's and caregiver's behavioral response patterns as previously listed should be correlated with developmental testing or assessment.

Intervention

1. Early intervention programs should provide year-long, 12-month services.

2. The frequency of home visits or other program services should be determined by family circumstances and the severity and complexity of the infant's condition.

3. All interventions should be integrated into the infant's daily routine as far as possible.

4. Parents should be the primary interveners whether the infant is receiving services in his home or in a facility.

5. Parents should receive explanation, demonstration, an opportunity to practice a return demonstration, and a brief written summary of all recommended interventions.

6. Toys and equipment in the home should be utilized or adopted for use whenever possible.

7. Use of new, controversial habilitative equipment and approaches should only be utilized under very strict, controlled conditions under the guidance of the appropriate professional.

8. Interventions for the advancement of developmental skills should be considered in conjunction with physical and psychosocial needs. For example, a commonly used strategy for increasing the infant's ability to attain and sustain visual contact with his caregiver is to instruct the caregiver to stop touching or talking and remove the bottle or breast each time the infant avert gazes. Interventions to increase visual contact during feeding are inappropriate for the infant who has nutritional deficit, and/or who needs to utilize brief periods of non-attention (avert gaze) during feeding as a mechanism for self-regulation.

Evaluation

1. Standardized tests and tools should be used to evaluate developmental achievements and the rate of change.

2. Narrative statements should be used to add empirical observations relating changes in the quality of performance.

3. Advancement or non-advancement of developmental achievement during the first three years of life should not be used to predict future performance or ultimate developmental outcome.

4. The evaluation of early intervention program services should be determined by a composite evaluation of the family's and infant's physical and mental health as well as their achievement of developmental milestones.

VI. THE ROLE OF THE STATE AGENCY

There are many federal programs providing support for early intervention services for infants, from 0 to 3 years of age, with discernible handicaps and their families. Each of these funding sources has its own legislative mandate, and there are no requirements at the federal level that these programs be coordinated and complementary. This has created a situation of overlapping authorities and responsibilities which has often led to the duplication, fragmentation, and gaps in needed services.

For maximum effectiveness and efficiency, the responsibility for the coordination of these services should be invested in a single designated state agency, and directed by the appropriate professional staff from within that lead agency. The state agency which administers the Title V program is the most appropriate one to serve as this lead agency. It is recommended that states plan for the coordination of services and that the program directors of the several agencies involved should participate in an Advisory Council which will be active in the development and annual review and update of the coordination plan.

A state early intervention plan should contain the following elements:

1. Assessment of Infant Needs

   a) Each state should have an adequate data base which would identify infants needing early intervention.

2. Assessment of Resources

   a) All existing resources within the state should be identified and utilized to the fullest extent possible in providing early intervention services eligible for infants.

3. Organization and Administration of the Services at State and Local Levels

   a) As the portal of entry is most frequently through health services, and as technology for recognition of handicapping or potentially handicapping conditions in the newborn and early infancy period is increasing rapidly, it is recommended that the State Title V Agency take a leadership role in early intervention services for children from birth to three years.

      Other agencies participating in the development and update of the state program should include those responsible for Mental Health and/or Developmental Disabilities; Special Education services; Medicaid; state or regional chapters of the American Academy of Pediatrics, and representatives of the private and voluntary sector such as child health and advocacy or service groups.

4. Description of Early Intervention Services

   a) There should be written theoretical framework and rationale as the basis for curriculum components, both assessment and intervention techniques, and the modes of service delivery.

   b) The narrative should define the population characteristics, criteria for eligibility, program focus, and the frequency and content of the services.

   c) Program goals for each family should include:

      . The identification of needs for additional health, education, and/or social services beyond those available within a specific program

      . Referral to and appropriate use of these services

5. Facilities: Home and Community Agencies

   a) The environment should be safe and should have supportive equipment and facilities with sufficient space (see existing laws and regulations for child care facilities in each state). Furniture should be child scaled.

   b) There should be adequate play materials. New controversial habilitative equipment and approaches should not be utilized unless under strict control.

   c) There should be provisions for the space necessary to convene parent classes or parent support groups.

   d) Nutrition consultation should be available to assist families and staff plan nutritious, age-appropriate food experiences.

6. Staffing Considerations (see Appendix C)

7. Standard Setting/Quality Assurance

   a) There should be a written description of mechanisms for standard setting for all components of services, including staff and program content of the early intervention programs.

   b) The state should review existing standards for children's programs to determine appropriate standards.

   c) Description of mechanism for quality assurance should include:

      1) Methods to insure referral of the individual child and family to a program of services able to meet the assessed needs.

      2) A system of monitoring and evaluation.

3) A consolidated records and reporting system upon which data collection and analysis is based and the results of which are to be used in monitoring and an evaluation system to determine the following:

a) The appropriateness, quality, and effectiveness of services for individual infants and their families.

b) The extent to which coordination with the agencies' services have been achieved.

8. Funding of Early Intervention Services

a) A method of securing and mixing funds for support of early intervention services from multiple federal, state, and local sources should be described. Currently, funds from Title I, Title V, Title VII, Title XIX, Title XX, DDSA funds, United Way funds, state and local funds, private insurance funds, SSI monies, etc., are being or could be used to fund services to handicapped infants and their families.

b) Submission of accurate cost data should be required for analysis based on cost per client data. Replicable evaluation models should be developed to establish a data bank and measure the effectiveness of habilitative and program approaches.

c) Programs should find means to secure reimbursement from private and public sources to finance statewide early intervention services.

9. Safety

a) Programs should meet the requirements for state and local fire codes and safety standards. Annual review of safety measures within classroom programs will include examination of: (1) the physical plant, (2) equipment and objects used by staff and children, (3) special care needs of individual children, and (4) transportation procedures.

10. Education/Training

a) Outreach activities should provide information regarding early intervention services to physicians, health/medical care agencies, and local education and social services.

b) The state program should identify activities to provide:

1) Orientation and continuing education for staff and the professional community about early intervention services.

2) Methods to impact generic professional education programs.

11. Record Systems

Each child should have an Individual Service Plan which is based on an interdisciplinary evaluation of the infant's specific medical, educational, developmental, psychosocial, and habilitative needs. The manual prepared for the SSI/DCP Program entitled Individual Service Plans is a useful reference. The plan is a part of the child's ongoing medical record and should utilize previous prenatal, natal, and neonatal record information.

12. Transportation

Transportation must be considered for facility-based programs. In the majority of circumstances it is assumed the parents would accompany the infant. Any infant transported to the program should be accompanied during the transportation by an attending adult. The standards for automobile safety published by the American Society for Automotive Safety must be followed.

13. Confidentiality

Each state program should assure that all personal information about recipients of early intervention services will be held confidential, and will not be disclosed without the individual's or parents'/guardians' consent. Otherwise, information will be disclosed only in summary, statistical, or other form which does not identify particular individuals.

14. Availability/Accessibility

15. Legal Issues

16. Advisory Boards

17. Monitoring and Evaluation

18. Collection and Analysis of Data

This outline contains the major items which a state early intervention program should include and to which special attention should be given. Suggestions as to how any of these items, particularly 14 through 18, should be expanded upon would be appreciated.

APPENDIX A

UTAH'S INFANT DEVELOPMENT PROGRAM

Presentation at a Conference

"HEALTH ISSUES IN EARLY INTERVENTION PROGRAMS FOR HANDICAPPED/DISABLED CHILDREN BIRTH TO THREE YEARS"

May 19, 1980

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UTAH'S INFANT DEVELOPMENT PROGRAM

I. INTRODUCTION

The State of Utah enjoys certain geographic and population characteristics that influence all services to handicapped children and their families. Seventy-five percent of the state's 1,300,000 residents live in the northern part of Utah along the western slope of the Wasatch Mountains. Specialized health and education services are also concentrated along the so-called "Wasatch Front," leaving other areas of the state with few specialized medical/health social or education services.

Utah has the highest birth rate in the nation. In 1978 there were 28.2 live births per 1,000 population compared to the United States' rate of 14.9; provisional statistics show Utah's birth rate for 1979 to be 29.9 compared to the U.S. rate of 15.0. Utah's rate of infant deaths for 1979 is well below the national average (Utah 12.5 and U.S. 14.2) which would suggest that Utahns have both large and healthy families.

For many years Utah's school systems have been actively identifying handicapped children needing special education services. A report based on school census data in 1974-75 has projected that in 1980 Utah will have an 18% prevalence rate of children with handicapping conditions! Currently education's "Child Find" project is not directly coordinated with Health Department efforts of early identification of handicapped children.

The predominance of the Mormon culture (well over 60% of Utah's population are members of the Church of Jesus Christ of Latter-Day Saints or Mormon Church) influences health needs and approaches. A high incidence of adolescent pregnancy contradicts Mormon values of chastity and the marriage relationship. The lifestyle of Mormon families includes abstinence from use of tobacco, coffee, tea, and alcohol, which possibly affects Utah's low infant mortality rate. Unfortunately, medical and nutrition quackery abound in Utah, and there is a provincial distrust of both doctors and any governmental services. Strong emphasis on family life and the value of children affect the acceptance of handicapped children by their families and the community. The strong neighborhood and church networks provide support systems for the child and his family. Genetic counseling, abortion of an abnormal fetus, and family planning are strongly rejected by many Mormon families. Suggestions to institutionalize a handicapped child or that parents need "professional counseling" are not well accepted; the family is taught that "the church" and family together can provide everything needed for a quality life. Parents receive instruction on child and family growth and development, methods of behavior management that builds self esteem, and other parenting skills in various church sponsored programs. Education for all is valued, although early child care services outside the home are discouraged.

II. HISTORY

Credit for the initiation of developmental services to handicapped infants in Utah belongs to Dr. Garth Myers, M.D., Director of the Birth Defects Clinic, Primary Children's Medical Center in Salt Lake City and Pediatric Neurology Consultant for Utah Department of Health's Handicapped Children's Services. In 1969 Dr. Myers urged the Nurse Consultant in the Birth Defects Clinic to extend

her practice into home-based interventions for handicapped infants that would incorporate individualized sensory-motor programming into the family/home routine. It was agreed that the local public health nurse was the person most qualified to assist families in such programs. In 1970 four nurses from two large health departments in the Salt Lake City area were trained by the nurse consultant to assist infants served through the Birth Defects Clinic in home-based, sensory motor programs.[2]

In 1972 the Utah Department of Health moved this program from the Birth Defects Clinic at Primary Children's Medical Center into the Maternal Child Health Bureau at the Utah Department of Health. All agreed that the pilot efforts of the Birth Defects Program had been successful and should be expanded to a state-wide Maternal Child Health-Public Health Nursing Program. By 1974 a curriculum for training public health nurses for the Infant Stimulation programs was in place, and DDSA (P.L. 95-602) funds were used to carry out training of public health nurses to provide services in every major health district in Utah. A portion of the DDSA monies was used to purchase a basic set of reference textbooks, other reference materials, and special equipment and toys for use by the nurses in demonstration or to loan to families served.

A major change occurred in 1975 when the name of the program was changed in order to reflect the broad thrust of the services provided. Prior to this time the program was called Infant Stimulation. The new title, the Infant Development Program (I.D.P.) was intended to reflect comprehensive efforts to ensure total development of handicapped infants -- physical and emotional wellbeing as well as the advancement of developmental milestones. At this time the new director of the Utah Health Department's Division of Family Health Services proposed that Maternal Child Health monies be contracted to local health districts to purchase a set amount of public health nursing time for the I.D.P. By this time, local nurses found it increasingly difficult to give the time to each family required to meet the objectives and goals of the I.D.P., and, therefore, services were variable throughout the state. I.D.P. standards were designed and several small contracts totaling $5,000 offered payment to local districts to carry out this state operated program.

The contractual arrangements between the state I.D.P. program and local health districts increased yearly, and by 1977 every health district/county department had at least one public health nurse carrying out the I.D.P. at the local level. The state I.D.P. Director provides: (1) the initial training, (2) conducts two inservice training sessions per year, and (3) also makes at least one site visit per year to each health department program. Consultation is given per joint home visits, record audits, and meetings with multi-agency groups as needed for coordination of local services.

The following content is utilized for preparation and ongoing inservice education of I.D.P. nurses (public health nurses and other nurses in child care settings).

Health Content -

- Pathophysiology of the most common handicapping/disabling conditions. Common health and medical sequelae of these conditions (complications, secondary handicaps, chronic functional health problems, etc.)

- Current diagnostic and treatment techniques and regimens.

- Basic physical examination skills, with emphasis on assessment of infant reflexes, muscle tone, and sensory function

- Infant nutrition, both assessment and guidance

- Health and medical resources in the community

Developmental Content -

- Normal sequence of motor, social, communications, and self-care skills

- Function, use and limits of the most common developmental screening and assessment tools (DDST, Brazelton Neonatal Behavioral Assessment Scale, and the Haynes Developmental Milestones-Reflex Wheel)

- Social learning theory as the principles are applied in behavior shaping approaches

Family Content -

- Styles and patterns of parenting

- Short-term (grief process) and long-term adaptive responses of the parents and other family members (Farber, Olshansky, Roos, etc.)

- Attachment process (N-CAST model of mother and infant tasks, work of Bowlby, Ainsworth, Mohler, etc.)

- Physical and social environment of family: assessment and intervention

III. PHILOSOPHY AND GOALS

This program is based on a combined pediatric, public health nursing philosophy which considers the infant and the family as a unit and views a multidimensional assessment and intervention process as the best method of promoting optimal health for the infant and his family. The program enlarges upon a basic nursing role in serving the young handicapped child and identifies three major areas of responsibility:

1. To support and maintain the family
2. To promote and maintain the infant's health
3. To facilitate the infant's developmental advancements

Traditionally, nursing and other health services to handicapped children have focused on the following needs:

1. Therapy and special care routines
2. Medications
3. Prevention of complications and/or secondary handicaps
4. Special equipment
5. Safety

The Utah Department of Health's Maternal Child Health staff have developed and utilized a model for Well Child Services, which has become the framework for the I.D.P. This model proposes that optimal health in the infant (child) is manifested in the following ways:

1. Adequate nutrition
2. Adequate patterns of physical and emotional growth
3. Achievement of milestones in motor, communications, social and cognitive development, and self care skills
4. Protection against preventable disease and injury
5. Absence of illness
6. Correction of correctable abnormalities

These wellness parameters direct goals for preventive, maintenance, and restorative services to the handicapped infant and his family by the nurse. Extensive experience with this population has prompted another model which represents a Cycle: Health Problems of Handicapped Infants (Figure 1). This cycle represents the basis and sequence of infant and family care designed to promote optional health.

IV. METHODS/APPROACHES

Referrals to the I.D.P. come from private physicians, hospital nurseries, parents, public health nurses primarily through services in Child Health Conferences and WIC programs, Handicapped Children's Services, Primary Children's Medical Center and other agencies offering medical care to young children. Referrals come both through the I.D.P. director's office and to the local health departments.

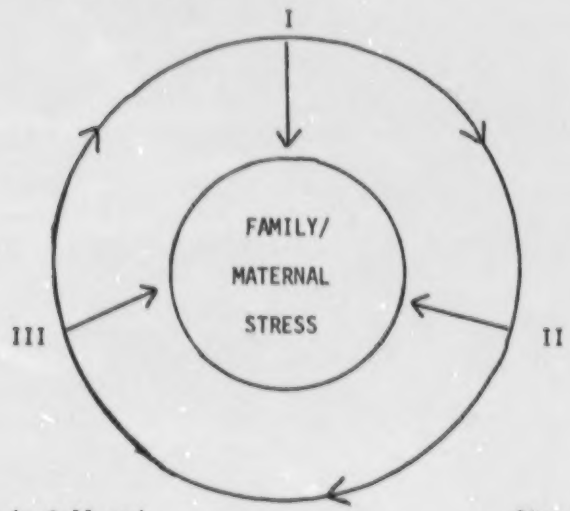
Assessments are multidimensional and include family history; assessment of the total home environment; the infant's health history; physical examination of the baby, including reflex assessments and identification of deviations in muscle tone, and sensory capacity of the child; nutrition status and level of feeding skills; and observations of developmental function. The Denver Developmental Screening Tool (DDST) is used to profile general levels of developmental function. The N-CAST model of parent-child interaction[3] is used to evaluate caregiver-infant interactive patterns. Use of the Sleep Assessment Tool also from the N-CAST project has assisted in the identification and remediation of sleep disturbances. Other physiologic rhythms are observed and assessed. Ongoing empirical observations of the mother/family and the infant in the home (their natural setting) offer opportunities for multidimensional interventions.

Interventions are both health and development oriented. The first major goal of assessment and intervention is to insure adequate nutrition and optimize the feeding experience for the infant and his caregiver. An effort is made to incorporate interventive techniques into the infant's daily routine -- diaper change, bath time, and during spontaneous and natural play times with mother and the other family members. Short written summaries are left with the parent which specify interventive techniques and approaches in terminology usable by the family. In cases where working with mentally retarded or illiterate parents, sketches and diagrams are used and left in the home for use by the family. In all interventions the nurse demonstrates the capacity of the infant to respond to a specific interventive technique as well as the ability of the caregiver to institute a

Figure I: Health Problems of Handicapped Infants

Step I. Pathology

A. Initial - Structural, Functional and/or Metabolic Abnormality
B. Secondary - added handicaps, complications and/or chronic illness



Step II. Feeding Problems and Decline in Nutritional Status

Step III. Decline in Cell and Systems Integrity

A. Physical Growth
B. Activity Level
C. Susceptibility to Infection/Illness
D. Elimination
E. Oral Health
F. Biorhythms, Response Levels
G. Vision Abnormalities
H. Reduced Appetite

technique successfully. A major challenge has been to plan success for both mother and infant. This is difficult when the infant is severely disabled and makes limited or very slow progress. Early sharing of care of the handicapped infant by the entire family, and, where indicated, use of respite care in order to promote equilibrium in the home and prevent "burn-out" by caregivers are encouraged.

Collaboration occurs at all levels of the program. The I.D.P. nurses utilize therapy consultation services from multiple sources; Handicapped Children's Services, Primary Children's Medical Center Services, local pre-school programs, private therapists, etc. Many infants on the program receive these services through their medical care agency, and the nurses can help carry out therapy instructions in the home as part of the total I.D.P. program. When the infant is between 24 and 36 months the family is referred to local pre-school services for admittance to a group-facility-based program. In some rural areas where preschool services are not prepared to serve multiply-handicapped children, these children remain in the I.D.P. until entry into a school program (in Utah the schools admit handicapped children at age 5 years). A written summary is sent to the preschool by the I.D.P. nurse which identifies health and developmental status of the child and recommendations for future care and service. Following referral to preschool, the child and his family usually remain on the caseload of a generalist public health nurse and receive traditional public health nurse services.

Services are primarily home-based and some local I.D.P.'s are now utilizing occasional small group sessions or "cluster groups" as a method of reaching families in a more cost and time-efficient mode. Public health nurses in rural areas find it time consuming and costly to make individual visits every 2-3 weeks to families in remote areas. The "cluster groups" have proved successful, and programs planned for these small groups have attracted fathers, grandparents, and neighbors. Topics which are easily adapted to this mode of service include nutrition, toilet-training, general use of behavior shaping techniques, and advancing feeding skills. Health Department specialists from the Genetics Program, nutrition consultants, psychologists, and therapists have assisted the nurses in these efforts. Every six months the I.D.P. nurse sends a brief assessment summary and the current intervention plan to the infant's medical care provider(s).

V. CURRENT SERVICES

Figure 2 shows the I.D.P. budget for FY 79 and the use of P.L. 89-313 (Title 1) funds and Maternal Child Health monies to fund this program. Since 1975 the I.D.P. as a state operated program has received Title I (P.L. 89-313)funds. This money has been used to hire full-time nurse specialists who are contracted to two local early intervention programs. One nurse, a pediatric nurse practitioner, provides extensive health consultation services in the state's largest early intervention program (Developmental Disabilities, Inc. Program - D.D.I Program) and two other nurses serve as case managers for approximately 50 infants in the D.D.I. program and Project PITCH, a second large early intervention program in Salt Lake County. The simplicity of the service and use of existing health systems and resources has resulted in low cost of service per infant/family. Over 150 infants and their families were served by fourteen I.D.P. public health nurses in health department based services, and nearly 200 infants and preschoolers received services from the three nurse specialists.

Figure II

UTAH INFANT DEVELOPMENT
PROGRAM

FY 80

I.	Title I Grant: FY 80	$ 76,000.00
	A. 3 Full Time Nurse Specialists 70 Infants - Case Manager 120 3-5 year olds, Health Consultation	
	B. 3 Months 1/2 Time O.T. Consultations	
II.	Title V: MCH	76,000.00
	A. Contracted time of 16 PHN's in local health departments Served 150 Infants	
	B. Administrative costs (approximate)	8,000.00
	C. Program Costs (approximate) (Staff development, training, travel, supplies, etc.)	12,000.00
III.	Other	
	Nurses in CC, Children's Hospital, Head Start, private practice, School for Blind participate on a limited basis. (no funds)	
	T O T A L	$ 172,000.00

220 Infants: Receive Case Management Services
120 plus: Receive Pre-school Health Consultation Services

During F.Y. 1978 a plan was developed by the I.D.P. to investigate the value of using a health consultation team to support existing Early Intervention (E.I.) programs for handicapped infants and preschool children. For nine months a pediatrician, the Maternal Child Health nutrition consultant, and the I.D.P. director studied needs and the results of health support services to three Salt Lake area E.I. programs; D.D.I., Project P.I.T.C.H., and Jordan Valley Preschool.

As a result of this study several changes occurred in all programs, and new data supported the need for providing similar services to all E.I. programs on a regular basis.[4] New forms were developed to speed and facilitate transfer of diagnostic data and other communications between physicians and E.I. programs and to organize medical/health data in the preschool record. Use of a pediatric nurse practitioner full time in one program (D.D.I.) resulted in reduced absence and identification of real reasons for absence in a preschool classroom. (See Tables I and II in Figure 3). The results of nutrition assessments and interventions on 42 infants/children validated the extreme need for this service as a regular part of E.I. programs and are shown in Table III, Figure 3.

Future goals for I.D.P. include the following:

1. Seek funds and support for a Health Team to provide regular consultations to local I.D.P.'s and other E.I. services throughout Utah.

2. Increase the number of infants served who have single and/or less severe handicaps or who are at risk because of cultural/social/economic factors.

3. Participate with Parent Education Resource Centers (19 PERC's in Utah are housed in local schools) to offer classes/assistance in teaching Parenting of Infants.

4. Carry out research and collect data to validate the results of home-based health focused E.I. services to handicapped infants.

Figure III

Tables of Absence and Nutrition Assessment Data. Reproduced permission of Division of Family Health Services, Utah Department of Health from unpublished report, Providing Health Care Consultation Services to Selected Early Intervention Programs, 1979.

TABLE I

Reasons for Absence
(February through May, 1979)

Reason	Number of Absences	Percent/Total Absence
1. Child ill	308	55%
2. Miscellaneous (family emergency, etc, or reason not determined by PNP)	93	17%
3. Transportation	54	10%
4. Other family member ill	33	6%
5. Medical appointments	30	5%
6. Out of town	29	5%
7. Weather	8	2%
Totals	547	100%

TABLE II

Absences Related to Child Illness

Days of Absence	Per Cent: Program Time Lost	Reasons
118	38%	Children ill, parents sought medical advice.
113	37%	Children ill, parents did not seek medical advice.
36	12%	Children hospitalized for surgery or serious illness.
33	11%	Children reported to be ill, but parents not reached for specific information.
8	2%	Child had seizures, sequelae prevented attendance.

Total of 308 absence days due to illness, February - May, 1979.

TABLE III

Major Nutrition Problems Identified:

	NUMBER
Inadequate dietary intake	31
Underweight for length or height	23
Small stature for age	15
Feeding difficulties	14
Overweight for length or height	13
Constipation	8

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APPENDIX B

HAWAII'S ENRICHMENT PROJECT FOR HANDICAPPED INFANTS

By

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University of Hawaii

The great law of culture is:
Let each become all that he
was created capable of being
Expand, if possible, to his full growth
and show himself at length
In his own shape and stature
be these what they may.

Thomas Carlyle

This presentation will describe Hawaii's demonstration project for infants with handicaps which was sponsored by the School of Public Health of the University of Hawaii, during the period 1972-75*. Funding for the project was provided by the Bureau of Education of the Handicapped**, of the Office of Education, Department of Health, Education and Welfare. I will not attempt to discuss the issues nor do a review of the research findings related to early intervention. We have already asked our two illustrious infant research consultants to do that.

PHILOSOPHY AND GOALS

The pervasive theme for care and caring for our handicapped infants and their families is that a handicapped baby is a baby who needs to be held, cuddled, and talked to. He also needs, at appropriate times, to be played with, and provided with all the care that any baby needs. Lemkau states that, "The problem for the person who wishes to preserve, as much as possible, the normal development of the personality of the handicapped child, is to see that the deprivation and under-stimulation he suffers are minimal." (Lemkau, 1961)

The goals of the Enrichment Project for Handicapped Infants (EPHI) were as follows:

1. To provide a program of enrichment for infants with handicaps as early as possible to help them towards optimal functioning.

2. To support the parents to enhance their interactions with their handicapped infant.

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* A slide-tape production entitled, "LET EACH BECOME" which describes the program was shown at the conference in May 19-21, 1980.

** Presently the Office of Special Education, Department of Education.

3. To enhance communication between parents and assist in relationships of siblings to the handicapped child and family.

4. To serve as a training center for university students from different schools and departments.

5. To promote early case-finding and referral whereby members of the community, particularly physicians and hospital nurses will be alerted to early diagnosis and referral.

In order to achieve the major goals of the project, emphasis was on an individualized program for each caregiver-infant dyad and their family. It meant (1) careful interdisciplinary assessment of the needs of the infant, (2) observation of the caregiver-infant interaction, (3) observation of the interactions of the family, the support system available through extended family or friends, and (4) appreciation of the cultural background of the families in the program.

Based on these observations and assessments, the staff collaborated with the parents in preparing a care plan for the infant and agreeing on outcomes for the parents themselves and other members of the family.

PROCEDURES

Eligibility and Assessment

The project accepted any child with a handicap from birth to 3 years of age. Referrals were accepted from various sources; parents, agencies, public health nurses, physicians, hospital personnel.

Following a referral, an appointment was made with the family for a staff member to visit them at home to explain the program and to obtain clearances from them to request data from their physician concerning their child. If the parents wished to follow through, an appointment was made for both parents to visit the center with their infant. At this time the infant was assessed by the team of physical therapist, occupational therapist, speech pathologist, psychologist, teacher, and nurse. While one person worked with the infant, the other team members would score their tests. Much of the assessment included asking the parent about the baby's behavior and having her work with the baby in demonstrating behaviors.

If the child had an orthopedic or gross motor problem, the physical therapist was usually the primary tester. This approach was to reduce handling the baby, also reduce the number of appointments the parents had to keep to complete the assessments by members of the other disciplines, to determine the level of the child's functioning, and to become acquainted with the mothers. The father was interviewed by the parent counselor to obtain demographic, social and medical information about the members of the family.

The parent and child were also videotaped in a play situation during their first visit to the Center in order to observe their interactions.

Program Schedule

Children were scheduled to come to the program 1, 2 or 3 days a week depending on the child's age and the severity of the handicap. A parent or parent surrogate accompanied the infant at least once a week so that he or she could receive instruction from his/her care manager and also attend the parent group meetings.

To facilitate the parent coming to the program, sessions were held from Tuesday through Saturday from 8 to 12 noon. The Saturday program was to accommodate working mothers. Fathers' groups and sibling groups were also organized and met on Saturdays so that all the family could participate in the Center activities. Those families who were unable to come to the Center for various reasons, were seen in periodic home visits by the family's care manager.

TRANSDISCIPLINARY APPROACH

In order to work with a group of children with the range of disabilities that were found in our program, we needed a staff that could attempt to respond to the varying physical, cognitive, social, emotional, and developmental needs of the infants in the program and their families.

At the same time, it was apparent that to have all of the staff handle this highly stressed infant and bombard the family with instruction would emphasize the family's perception of the child's atypicalness rather than his need for a normal environment.

To allow for the expertise of the respective professional specializations and the fact that parents have to learn to carry out the different therapies, the transdisciplinary model was utilized. (Haynes, 1976; Hutchison, 1974)

THE CURRICULUM

HELP Chart

The HELP Chart and Guide (Furuno, et al, 1979) a normal developmental scale, divided into six developmental areas for children, birth to 3 years of age, was designed during the course of this project. The scale was organized in small, incremental steps on a month by month basis, so parents and children could experience successes rather than repeated frustrations, particularly for the severely handicapped child. The majority of the children in the program were those who were discovered early, frequently at birth, and who, therefore, tended to have severe handicaps. The scale is presently being used by all infant centers in Hawaii as well as in many programs throughout the country.

Group Program for Caregiver and Child

The program at the center usually began with a music session conducted by the teacher with both parent and child participating. An effort was made to integrate gross and fine motor, language, and cognitive and social goals. Positioning and placement of the children according to their development and

handicapping condition were important considerations. Children learned to identify themselves and others, to use cues, to respond to verbal rewards, and to make choices during this large group session. Parents could observe their child's interactions with peers, their response patterns, and staff approaches to enhance their development.

Home Activity Sheet

Following this large group activity, the children and parents were seen by their care manager who prepared a weekly activity sheet based on the objectives outlined in the child's care plan. The activities listed were demonstrated to the parents followed by a return demonstration. Parents were asked to take the activity sheet home and indicate whether the activities were too simple or too difficult, and to make any additional comments. They were advised that the activities should be integrated with other adult or sibling interactions and regarded as play for the baby, not something to do at a specific time repetitively.

Classroom Activity Sheet

Besides the home activity sheet, classroom activity sheets were also prepared on a weekly basis. Each child had a program written out for him so that staff would know exactly what activity would be appropriate for him. Additionally, the Center involved a number of students from the University of Hawaii engaged in their practicum or field work. For them to be able to interact with a child they needed to know what his functioning level was. The classroom sheets facilitated this process.

Small Group

Small group sessions were also scheduled in which children who were functioning at close to the same levels in fine motor development, for example, would work with the occupational therapist on fine motor games. Children with similar cognitive level skills would have a lesson together. Even in these small group sessions, the activity was individualized because of the children's diverse levels of functioning.

Lunch and Snacks

Lunch and snack times were also important teaching and learning periods. Nutritious snacks were prepared by the staff and used for introducing new foods, tastes, and textures for the children. It was also a time for parents to learn feeding skills if any of them were experiencing problems. Sweets and sugar products were avoided as much as possible. Parents prepared the children's lunches, which reflected the family's ethnic background.

Each year a graduate student from the School of Public Health's nutrition program took her practicum with the program and provided diet counseling for the parents.

Toileting and dressing activities were also part of the day's program to help the child develop self-help skills according to his developmental age.

FAMILY PROGRAM

In the initial sessions with the family, when the baby's care plan was being formulated, parents were also asked what goals they had for themselves and their other children. These were written out and reviewed periodically, primarily by the parents themselves.

Parents attended parent group sessions once a week, and these were conducted by a psychologist. These sessions were designed to help parents interact with others, and to reduce their feelings of aloneness. The parent groups also allowed the parents to express their feelings about their babies, their families, and themselves, and to become more knowledgeable about the condition of their children. Additionally, sessions were used for explaining the role and function of each of the therapists, their intervention techniques, and explanations of the individual treatment programs that were prescribed. These presentations were videotaped so staff would not have to be present at each of the parent group meetings (2 to 3 different mothers' groups per week, two fathers'groups per week) and the parents could also view them at their leisure. Individual sessions with parents were also arranged with the psychologist or physician when appropriate. Additionally, any necessary social work or public health nursing services were easily arranged with the Department of Social Services and/or the Health Department or the social worker at Sultan Easter Seal's School for Handicapped Children.

Fathers' group meetings were held once a week in the evenings and on Saturdays. Forty-five percent of the fathers in the program attended these meetings regularly. A total of 67 percent of the fathers attended at least one of the sessions. These were conducted by male graduate students from the Department of Psychology and the School of Public Health at the University of Hawaii.

Parents additionally organized a Parents' Association and held monthly meetings to listen to speakers, discuss parent concerns and the project's future. Specially trained baby sitters were made available to care for the babies and their siblings during these meetings. Activity programs for siblings of the handicapped infants were also held on one Saturday of each month.

MEDICAL MANAGEMENT

The medical consultant and the public health nurse assigned to the project were responsible for the medical management of the children. Many of them were already known to the medical consultant because of her affiliation with the Birth Defects Center. Either she or the nurse contacted the family's private physician when there were any problems. Conferences concerning each of the children and the families were held with all of the team members present to establish and review the child's care plan. The nurse was present at all of the conferences and the physician at most of them. The physician also visited the Center periodically to see all of the children and review their progress.

Referral sources were kept well aware of the progress about the infant. The children's physicians were notified of the family's acceptance of the project, asked to provide information, sent follow-up reports when children were evaluated at the end of each year, and again when they were discharged at 36 months and

placed in other programs.

STUDENT TRAINING

The program was very popular for student field work and practicum. A total of 108 students were involved in 1974. These student programs ranged from once a week volunteer or field work sessions for undergraduate students to special projects for graduate students, and full semester practicums for special education teachers (one each semester). Two staff members for a crippled children's program in Micronesia came for one semester each and participated in all facets of the program working alongside different staff members. Students participating at the Center were from the Schools of Public Health, Medicine, including the Department of Speech Pathology, Nursing, and Social Work; the Department of Psychology, the College of Education, and the Department of Human Development of the University of Hawaii.

RESULTS

The project served 110 infants from 1972 through 1975. Since then project staff were involved in training and data collection for the infant programs disseminated throughout the state. A total of ten centers are presently maintained by public and private funds. To obtain funds from the legislature initially, parents of the Enrichment Project contacted 74 of the 76 legislators in 1975 and were successful in having the budget passed to support these infant programs.

Model components of the project which are continuing to be used by programs in Hawaii include (1) the individualized care plan, (2) the transdisciplinary approach, (3) the HELP Chart and Guide, (4) the parent program with differences in the extent of therapeutic groups, (5) the center program with home visits for those unable to attend, and (6) the appointment of an educator for each of the infant programs.

Rather than report on data presented on an annual basis in between 1972-1975, where the N's were quite small, I would like to report on data from the infant programs in Hawaii. The results presented here are based on 390 children who were served in 7 of the 10 infant programs from July 1, 1977 to June 30, 1978, the data which the EPHI staff collected and analyzed annually from 1976 through 1978.

Diagnostic Categories

As shown in Table 1, more boys than girls were in the program: 56 to 43 percent respectively. Of the diagnostic categories, the largest group was the developmental delay and/or high risk group, followed by the mental retardation group. The latter included all categories under mental retardation in the AAMD Classification Manual, but excluded Down's syndrome. Down's syndrome children comprised only five percent of the total population in the program. This is in contrast to approximately 25 to 30 percent of the population of children found in our Enrichment program during the project period.

Referral Source

The major referral souce for the seven Hawaii programs was public health nurses. As seen in Table 2, they were responsible for 35 percent of the referrals, followed by physicians with 21 percent. In our project, because the majority of the children tended to be those with specific or multiple discernible handicaps, the major referral sources tended to be a pediatric neurologist to whom most handicapped babies were referred, the Department of Health Crippled Children's Division, and private physicians. The youngest children in our project were referred by private physicians, the pediatric neurologist and the Birth Defects Center.

Ethnicity

That handicaps do not discriminate is strikingly indicated in Table 3, which presents a picture of handicapped children by ethnic groups. All the ethnic groups have fewer handicapped infants than expected from their respective population groups except the Hawaiian and part-Hawaiian. The Filipinos and Asian groups (excluding Japanese) seem to have approximately the same percentage of handicapped for their population sizes.

Thirty-two percent of the Hawaiian/part-Hawaiian handicapped fell into the high risk/developmentally delayed group. This is related to prematurity, lack of early prenatal care and teenage single motherhood. (Department of Health, 1977)

One-fourth of the handicapped in the Filipino population fell into the category of mental retardation, while close to another fourth are developmentally delayed/high risk. Of the handicapped group among the Japanese, Down's syndrome babies comprised 10 percent, the highest percentage in all the ethnic groups. In the Hawaiian population, those infants represent 1 percent of its handicapped. (See Table 4)

Parental Change

To evaluate some of the changes that occurred among parents, a tool entitled the Growth and Development Inventory was designed. It consists of multiple choice, true-false and sequence ordering questions pertaining to normal growth and development of infants. Questions related to attitudes, knowledge, and skills about handicapped children.

Due to a number of factors, such as language barriers, late entry into the program, continuing families, only 92 parents are included in the pre-post inventory. This inventory is given to all new parents on entry and a post-test given at the end of the year. Mean differences between the pre-post tests were found to be highly significant in the skill and knowledge areas, but no difference was noted in attitudes. The fact that parents are participating directly in enhancing the child's skills, and are also interacting closely with the care manager, and can observe the child's progress with the aid of the HELP chart may explain the change in these areas. Their attitude scores during pretest tend to be high enough that no change is necessarily indicated. (Table 5)

TABLE 1

Number and Percentage of Children in Infant Programs in Hawaii:

7/1/77 - 6/30/78

Total Number of Children	No.	%
Male	222	56
Female	169	43

Diagnostic Categories	No.	%
Developmental Delay/High Risk	101	26
Mental Retardation	59	15
Language Delay	33	8
Other Orthopedic	31	8
Other Health	22	6
Cerebral Palsy	30	8
Down's	19	5
Deferred or Undiagnosed	8	3
Child Abuse	5	2
Normal	5	2
Blind	3	1
Hearing Impaired/Deaf	1	.5

TABLE 2

Number and Percentage of Referrals By Source

Referral Source	No.	%
Public Health Nurse	137	35
Private Physician	81	21
Family/Friend	41	11
Department of Health	38	10
Clinic Physician	31	8
Hospitals	28	7
Private Health Agencies Hawaii Association to Help Retarded Citizens (HARC) United Cerebral Palsy Assoc. Easter Seal	9	3
Other	16	4
Dept. of Social Services & Housing	5	1
Child Protective Service	3	1
Waimano	1	1

TABLE 3

PERCENTAGE OF HANDICAPPED INFANTS

By Ethnic Background of Mother

Compared by Total Population in Hawaii

	Handicapped Infants %	Total Population in Hawaii %
Caucasian	32	39
Hawaiian/Part Hawaiian	26	9
Japanese	17	28
Filipino	13	12
Chinese	2	7
Other Asian	2	1.5
Black	1	1
Mixed Ethnic Background	6	2.5

TABLE 4

DIAGNOSIS BY ETHNICITY OF MOTHER

	Japanese N-63	Caucasian N-97	Hawaiian N-100	Filipino N-48
	%	%	%	%
Cerebral Palsy	5	10	6	10
Language Delay	6	11	9	4
Mental Retardation (Excluding Down's Syndrome)	13	14	10	25
Down's Syndrome	10	6	1	4
Developmental Delay	10	11	22	15
High Risk	10	6	10	8
Orthopedic Conditions	3	5	2	2
Neurological Conditions	2	7	2	4
Other Health Conditions	6	2	4	6
Miscellaneous Conditions and Missing Data	35	23	34	21
TOTAL	100	100	100	99

TABLE 5

PARENTS PRE-POST RESULTS ON

CHILD DEVELOPMENT INVENTORY

	N	MEAN		DIFFERENCE	P
		PRE	POST		
ATTITUDE	92	7.99	8.14	.15	.28 N.S.
SKILL	92	9.77	10.68	.91	.001
KNOWLEDGE	92	16.60	18.46	1.86	.000

In evaluating parental changes, the Enrichment Project used a family inventory on a pre-post basis with an interval of about nine months related to increase in (1) independence of the child, (2) participation in educational activities at home, (3) positive reinforcement behavior and use of diversion for discipline, and (4) parental accord and communication. The inventory was evolved from an interview scale developed by Raeone Zelle as part of her master's thesis in nursing at the University of Washington. (Zelle, 1969)

Results indicate that the degree of independence demonstrated in play activities by the children were considerably enhanced by participation in the program. Additionally, mothers were participating more actively and fathers to an even greater extent. Approximately 70 percent of fathers in the program spent more time with their disabled child following participation in the program. Statistically significant results were obtained at the .01 levels for child independence and educational activities at home.

In relation to behavior and discipline, no significant changes were noted in the child's reaction to discipline, i.e., according to the parent, the child was not responding much more to reinforcement nor was the child easier to manage.

Results related to parental accord and communication indicate no change. In fact, the trend seemed to be that parents experienced more differences in their perceptions of whether one parent was stricter than the other, or whether they agreed on child care methods. While results were contrary to our expectations that groups would demonstrate a greater degree of harmony, the staff tended to feel that the parents' ability to acknowledge differences may be healthier, particularly in the ethnic groups we served, and reflective of real rather than imagined parental accord. I am reminded of a scale that we had intended to use measuring parental feelings such as depression, anger, etc. During initial testing it appeared that parents were in such high spirits that no way would we have been able to see change except by a depression in the scores.

Change in Children

To measure change in the children's functioning, the HELP chart was used to determine whether objectives in each of the six levels were achieved, not achieved or exceeded.

Results indicate that for all skill levels except language, 71-79 percent of the children reached or exceeded the objectives written for them. Only in language was there only 49 percent achievement. (See Table 6)

Pre-post results by diagnostic categories are indicated in Table 7*. All children in the respective diagnostic categories show gains. The extent of these gains in the different skill areas is indicated in Figure 1.

The "other health" group relating to children with heart defects, blind, hearing impaired, neurological problems, failure to thrive, had the greatest change in cognitive and language development. The group that showed the smallest differences in all areas was the mentally retarded group, excluding Down's syndrome children.

TABLE 6

Objectives Fully Reached or Exceeded Over a 6 mos. Period

Cases	Objective/Score	Fully Reached	Exceeded
200	Cognitive Objective/1	126 (63%)	27 (13%)
126	Language Objective/1	53 (42%)	9 (7%)
199	Gross Motor Objective/1	105 (53%)	42 (21%)
198	Fine Motor Objective/1	106 (53%)	35 (18%)
195	Social Emotional Objective/1	118 (61%)	33 (17%)
195	Self Help Objective/1	109 (56%)	36 (19%)

Children with Down's syndrome showed large gains in fine and gross motor skills. Their gains in cognitive skills were also close to gains by other groups.

In addition to using diagnostic categories, because of the intra-group variability, attempt was made to separate groups into high, medium, and low based on their pre-test scores in each of the skill areas. Comparisons of relative gains for each of the skill areas as a function of their pre-test scores in each area were then made.

Out of a possible 36 comparisons, 11 showed that the gain was differentially related to pre-test levels to a significant degree. (See Table 8)*

*Table 7 and 8 not available at time of printing.

Results indicate that children who scored high in self-help, fine motor and language skill areas showed large gains in language. In contrast, the greatest gain in fine motor skills was observed in those children scoring low in all areas of initial testing.

Besides the above, I would like to describe those results from the demonstration project that were not quantified, but may be reflective of the real effects.

1. A number of the mothers met to ask whether they could have their children attend an extra day for which they themselves would assume responsibility with opportunity to consult with the staff. Most of these mothers had started in the program when their children were less than a year old, and some of them were already using the HELP Chart to write their own activities for their children. With staff help they agreed that three of the mothers would conduct a nursery school type program at the Center on Mondays when the staff were not present. The preschool classrooms at Sultan Easter Seal School, which had a program Monday through Friday, were in session. Seven children who were between two and three years of age, without severely involved handicapping conditions were invited to attend. One of the mother-teachers had been an elementary school teacher before the birth of her child. Another, a high school graduate, decided to enroll at the University of Hawaii to become a special education teacher.

2. One of the parents, a nurse, whose child was severely handicapped and hospitalized more often than not, but who ended up with a number of others in a regular pre-school, became a co-therapist for the mothers' group and continues to do so at the Easter Seal School.

3. Parents of some of the children who were referred to our program for a mild handicap, who were quickly moved to the infant program for disadvantaged children and to the Parent-Child Center, wanted to continue to have the child come to the program at least once every two weeks so we would be able to help prepare his/her weekly activity sheet.

4. A number of families still maintained interest in the Center even though their children were placed in other programs at 3 years of age. They continued to attend our parent meetings, volunteered for committee work, asked for teaching materials, and volunteered to assist with construction and repairs.

Some of the parents' comments about the group sessions and program indicate the importance and need for such infant programs.

"I enjoyed every minute. Teaching my child means a lot to me."
"I learned to express myself, to appreciate that I'm not the only one with a retarded child."
"I got something from every meeting, some for my child and some for me."
"I especially realized how I felt about my mother and sister."
"The mothers' meetings helped me in more ways than I can say."

Dr. Edward Martin, Deputy Director of the new Department of Education, has stated, "We need to set a goal for the 80's to serve every handicapped child from birth on." (Martin, 1979) Presently 10 states have legislative mandates for eligibility at birth and five states have permissive legislation at birth (CED, 1979). With schools beginning to assume responsibility for preschool children with handicaps, it may well be that health programs need to take leadership for infant programs for the handicapped.

If, as Dr. Martin states, this nation will serve handicapped children "from birth on," there needs to be more solid information about the most efficient, beneficial and cost effective intervention programs. Questions such as what is optimum staffing? How much stimulation? When is the optimum age for a child to begin a program? Home or center based programs, is it a question of which is better or when to use which? How frequently should a child be seen? What do we know about the best ways of "turning parents on" to their handicapped babies? What are the long-term effects of infant intervention programs for the handicapped?

We would hope that the answers to some of these questions will help us to enhance our services to handicapped children and their families and allow us to continue to serve this special population in the most humane, the most efficient, and the ultimately beneficial way for all concerned.

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APPENDIX C

STAFFING CONSIDERATIONS

1. The early intervention team members should be qualified by education and experience in infant and family development with special emphasis on habilitation. Education should include theory and clinical practice in the care of normal infants and their families, as well as those with discernible handicaps.

2. Licensure/certification requirements of the state must be met. These vary according to discipline and state.

3. The early intervention program may be directed by a professional from the disciplines of health or education who meets qualifications outlined in #1.

4. Paraprofessional staff and volunteers must be supervised by qualified professional staff.

5. Consultants should be available on an ongoing and regular basis whenever they are not members of the team providing direct services. This would include consultants in speech and audiology, physical therapy, occupational therapy, nutrition, social work, psychology, developmental pediatrics and pediatric nursing, and special education.

6. Technical assistance and consultation in health matters should be available through designated health department personnel at the state and/or local levels including speech and audiology, physical therapy, occupational therapy, social work, psychology, developmental pediatrics and pediatric nursing.

7. Ratios of staff for services depend on the severity of handicaps of children serviced, the mode and components of services provided, geography of the state and/or local area, and the availability of consultants.

8. Minimum health requirements for staff should include up-to-date immunizations, tuberculosis screening, and absence of infectious disease.

9. Conversely, pregnant staff should be informed of reports of infectious diseases or other risk factors concerning enrolled infants which could endanger a developing fetus. (Toxoplasmosis, rubella, cytomegalovirus, herpes)

10. A line item of the annual budget should be available for staff in-service training that is correlated to the program's characteristics and needs of the infants and their families.

11. Parents and staff should receive regular instruction and training in general first-aid and emergency care techniques including, but not limited to, the Heimlich maneuver for infants, cardiopulmonary resuscitation (CPR) and poison control measures.

12. Food handlers should be in compliance with the state health regulations.

During the conference, there was discussion about qualifications promoted by individual disciplines for Early Intervention Programs. Qualifications are especially important because all health disciplines do not require theory and practice in the care of infants and young children in their curricula. Therefore, it is crucial to recruit individuals who are specifically qualified by training and experience in normal growth and development and well child care and care of infants and children with developmental disabilities.

Standards adopted for any discipline should be recommended by that discipline's professional organization. For example, the Maternal Child Health Division of Practice of the Massachusetts Nurses' Association developed a position statement on the role of the nurse in Early Intervention.* The statement has been accepted by the Massachusetts Nurses' Association and by the Division of Maternal and Child Health Nursing Practice of the American Nurses' Association.

The position statement recommends a clinical nurse specialist, i.e., a nurse with a master's degree in pediatric or parent/child nursing. The clinical nurse specialist uses a body of applicable knowledge concerning the psychosocial development of individuals from conception through the childbearing and child-rearing phases of development. It includes knowledge of the interplay between the intrinsic and extrinsic environmental factors which enhance or deter the maturation of the infant and his/her family.

*A Call For Action on Behalf of Children: American Nurses' Association, Division on Maternal and Child Health Nursing Practice, 1980.

APPENDIX D

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APPENDIX E

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